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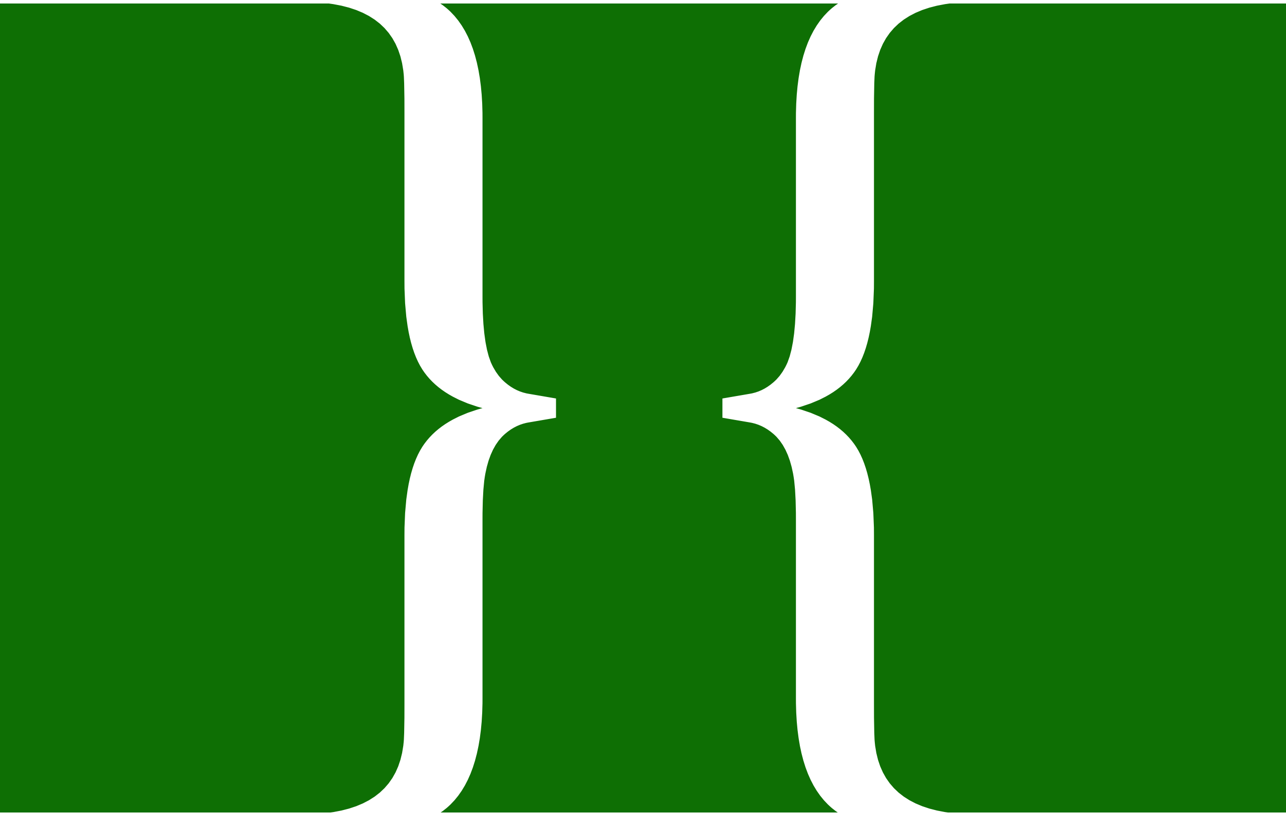

SOCIAL DISTRIBUTION OF HEALTH

KWARTALNIK
GDAŃSK 2022–2023

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Jacek Mianowski[1]
Agnieszka Borowiec[2]

Introduction

The Constitution of the World Health Organization defines health as "a state of complete physical, mental and social well-being" (WHO 2020: 1). However, the health condition of individuals and social communities is determined by various socio-cultural factors that may cause social inequalities in terms of health. On the one hand, they may result from natural differences (e.g., a person aged 20 may be in better health than a person aged 60). On the other hand, the health dimension of social inequalities (Sokołowska 1991) may be the result of differences considered unfair or result from injustice, such as in the case of limited access to health care (Kawachi, Subramanian, Almeida-Filho 2002: 647–648). Health inequalities, for instance due to age, can be analysed in scalar values, because the quantities are unequal but measurable (Arcaya, Arcaya, Subramanian 2015: 2; Braveman 2016: 34). Inequalities that refer to differences in health or their determinants that cause marginalisation or social exclusion of a person or group are interpreted in terms of injustice (health inequities). Health inequalities in this sense are the result of a normative assessment, on the basis of which inequality is interpreted as harmful (Arcaya, Arcaya, Subramanian 2015: 2).

While natural inequalities are difficult to avoid, inequalities considered unjust can be remedied by corrective actions. Therefore, the first step necessary in diagnosing the health condition of a person or group is to reveal harmful inequalities and to determine values on which the corrective action is to be based (Ruger 2016: 70). In this context, mechanisms for the social distribution of health are needed to ensure the equitable distribution of health resources and the correction of avoidable health inequalities. However, this requires the cooperation of individuals and social communities to improve the health condition of all those concerned.

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The articles in this volume are an attempt to diagnose the situation and health needs of groups exposed to various forms of exclusion or marginalisation in the health sphere (e.g., due to place of residence, age, disability or cultural differences). The authors try to identify the causes and effects of the health condition of their subjects and present the examples of projects and recommendations intended to change their health condition. The common denominator of the texts is searching for the answers to the questions: how and by whom and/or what can the mechanisms of social distribution of health be corrected?

Andrzej Jarynowski and Monika Wójta-Kempa analyse the structural conditions of COVID-19 vaccination in Poland in order to assess the solutions taken to combat this epidemiological threat. The authors assume that differences in the level of vaccination coverage highlight the problems of inequality in access to health care. In their analysis, they show inequalities in the estimated vaccination coverage and its predictors at the level of county. The main dependent variable was the percentage of full-scheme vaccination coverage in a given county. The explanatory variables included social, political, demographic, economic and epidemiological predictors. The results of the study suggest the influence of systemic (organisational) barriers on the level of vaccination coverage. The analysis allowed the authors to select counties at risk of exclusion, such as rural and small towns of eastern Poland, and districts potentially at risk, dispersed in clusters throughout Poland. Due to the fact that peripheral regions (with high support for the ruling party) have more problems vis-a-vis the vaccination campaign, the authors recommended that selected communes and counties be strengthened in personnel, information and medical terms in order to eliminate inequalities in access to health.

Magdalena Wieczorkowska examines the causes and effects of the ageing of the society. The author presents the demographic situation of Poland and the resulting challenges for health care, the issue of ageing in the context of health, and the tasks and goals of health promotion and prevention. In the theoretical aspect, the author highlights the assumptions of health policy in the field of health prevention and promotion among the elderly and checks whether health programs address the elderly. According to the author, health prevention and promotion are of key importance in the health care of elderly people who experience declining health. They are also relevant in delaying and mitigating the effects of ageing. In the empirical dimension, the author analyses the results of health policy programs and health programs at the national level, taking into account the criterion of age.

Edyta Janus assumes that man is an occupational being, and occupation is an active element of human existence necessary to maintain health in the sense of the word as broadly understood. Occupation is one of the basic human needs and refers to all the activities that people need or have to do and that are expected of them. The author puts forward the thesis that the right to perform activities that are important for an individual, inscribed in the idea of occupational justice, is often not covered by the opportunities available to people or groups struggling with various limitations (e.g., disabilities or mental disorders). In the assumed context, the author analyses the possibilities of applying the idea of occupational justice within the realities of Polish health and social care addressed to people with mental disorders.

Magdalena Sosnowska studies the selected aspects of meeting the intimate/sexual needs of people with disabilities by sex workers, sexual assistants and surrogate sexual partners. Referring to research results, the author presents aspects of this phenomenon in the legal, ethical, social and medical context on the example of solutions applied in several countries.

Jacek Mianowski analysed the process of cooperation between blind and sighted people during a seagoing integration cruise. In the theoretical dimension, the author refers to the assumptions of the integrative model of disability, an important component of which is social integration between able-bodied and disabled people. On this basis, the author understands integration as the result of joint sailing activities of people with different visual perception who participated in the cruise on the *Zawisza Czarny* ship. In this context, the author puts forward the thesis that the integration during a sea voyage is the result of the readiness of able-bodied and disabled people to create a “common world”. Therefore, the author conducted qualitative research to verify this thesis. Data from in-depth interviews and documentation were used to identify social and spatial factors that determine integration of able-bodied and disabled people during a sea voyage. In the spatial dimension, integration of the participants of the sea cruise was determined by the ship architecture and the security system that allowed for safe movement in the enclosed space of the ship. Social integration was shaped by the principle of dividing the participants into mixed watches, which were proportionately made up of blind, visually impaired and sighted people.

Anna Skiba analysed the social distribution of health in terms of differences in the perception and reception of diseases and their symptoms, on the example of *ngamuk*. In its empirical layer, the text is based on the results of ethnographic field research conducted in 2019–2020 based on the theory grounded in Indonesian Yogyakarta. The data comes from in-depth, semi-structured interviews about the cultural image of mental disorders. Western medics, traditional healers and students participated in the interviews conducted by the author. The statements of the Indonesians are used to build the social image of a mentally ill person as one who, to a large extent, exhibits aggressive behaviour towards others. The results of the study indicate that although none of the respondents used the word *ngamuk* when describing mental illnesses, the symptoms cited were close to the symptomatology of this disorder. Comparing the results of this study with the outcomes of other research on the cultural perception of diseases, the author concludes that the social perception of mental disorders is strongly culturally relativised. The example of *ngamuk* shows that the image of the affliction can be socially distributed.

You are welcome to read the texts contained in this volume. We hope that the analyses will make you reflect on the causes and effects of the social distribution of health and inspire you to undertake your own research on this subject.

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ARTICLES

Miscellanea Anthropologica et Sociologica 2022–2023, 23(4)–24(1): 11–34

Andrzej Jarynowski[1]
Monika Wójta-Kempa[2]

Social Geography of COVID-19 Vaccinations and Inequalities in Access to Medical Services in Poland

There is a need for a spatial analysis of COVID-19 vaccinations in Poland in order to assess the solutions taken to combat this epidemiological threat. Differences in vaccination rates highlight problems of inequality in access to health care. The analysis presented here aims to show inequalities in estimated vaccination rates and their predictors. The disparities were analysed at the NUTS-4 district level. The study uses spatial exploratory and statistical techniques in applying a model of the determinants of vaccination rates at the district level. The main dependent variable is the percentage level of full-scheme vaccination in a given district, and the independent variables were social, political, demographic, economic and epidemiological predictors. The results suggest a strong influence of systemic (organisational) barriers on vaccination rates. The proposed model using only a few key socio-epidemiological variables explains >75% of the variation in vaccination rates between districts (in particular, political preferences – specifically the choice of the party currently in power – explains as much as 30%). As a result of the analyses conducted, districts at risk of exclusion were selected, i.e., mainly rural and small-town districts of the eastern areas of Poland and districts potentially at risk, dispersed in clusters throughout Poland. Given that, peripheral regions with high support for the ruling party, fare less well in the vaccination campaign, the selected municipalities and districts should be strengthened in terms of personnel, information and medicine, with the aim of levelling out inequalities in access to health.

Keywords: vaccination, COVID-19, social geography, health inequalities, access to health care

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Introduction

Compared to other EU and OECD countries, Poland is characterised by large disparities in access to medical services (Cianciara 2015; Libura 2020). Social inequalities in access to health are diverse and encompass many socio-economic characteristics. The causes of inequalities may be of supply-related nature (number of physicians, distance from a clinic or a hospital, availability of procedures) or may be demand-related (health need/awareness, fear of becoming ill, willingness or unwillingness to be vaccinated, trust in professionals, etc.). The social factors of health inequalities are an important element in determining priorities in public health. From this perspective, health challenges (such as the COVID-19 pandemic) need to be associated with an analysis of the social factors that determine public safety. A sociological point of view brings not only theoretical contributions to the health sciences, but also the analysis and evaluation of solutions applied, for example, in the area of safety management.

In 2019, 4.2% of the Polish population reported unmet needs for medical examinations due to cost, distance or waiting time (the EU average was 1.7%). There were differences between groups with different incomes: 5.7% of the poorest people (from the lowest income quintile) reported unmet needs compared to 3.3% of the richest (OECD 2021). The basis of access inequalities hindering the satisfaction of healthcare needs is primarily the number of physicians per population, and systemic barriers, such as queues to specialists or the cost of alternative (private) services. The issue of existing disparities in the availability of medical services, including vaccinations, is a very important aspect of public health, but also a challenge for social researchers. In this study, we would like to draw the attention of social researchers to the spatial aspect of inequalities in access to vaccinations.

The social geography of inequalities in access to medical services is a rare topic addressed in the field of sociology. The basis for ensuring equal access to health should be the allocation of infrastructure and human resources made on a rational basis and based on analyses such as maps of health needs. In Poland, however, maps of health needs have a low cognitive value (they are mainly based on existing data) and are not used as a basis for decision-making. The organisation and allocation of services is political rather than expert-based in Poland. Additionally, the pandemic has highlighted and exacerbated some of the problems of the health care system in our country. Therefore, we decided to look at the social geography of vaccinations in the light of socio-economic variables to explain the impact of these factors on vaccination rates for COVID-19.

The social geography of vaccinations

Social inequalities in access to health services can be described as a problem at the intersection of sociology (including at least some of its sub-disciplines, such as sociology of medicine, sociology of social inequalities, urban sociology), health geography (formerly medical geography), and public health (Hill 2020). The approach presented in this article corresponds to Learmonth's concept of analysing the socio-spatial aspects of disease and health (Learmonth 1979). The tasks of the social geography of inequalities include, among others: analysing the spatial organisation of health system resources; assessing the optimisation of the spatial organisation of the system; and characterising the population benefiting from health care services (Rosenberg 1998).

The pandemic has created a new system of vaccination challenges. New factors, including access to medical knowledge and exposure to an environment unfavourable to vaccination, were superimposed on the old divisions resulting in lack of access to medical services (Yeast et al. 2015). The pandemic showed that many of the determinants of good health remained underestimated in public safety decisions, including the organisation of health resources, and arranging medical systems in spatial, financial and staffing contexts. These factors could include, for example, trust in medical personnel or vaccination culture.

The desire to contain the COVID-19 pandemic and reduce its impact has necessitated continuous monitoring of vaccination rates and spatial and social disparities. Analyses of the social barriers to vaccination rates have been undertaken in many countries from both the demand and the supply aspects. Attempts have been made to describe the relationship between COVID-19 vaccination rates and access to health care in spatial terms, such as analysing the distance from the vaccination point (Bump 2021). Among other things, interactive maps were created that could be used as a tool to support government-led vaccine distribution. It has been recognised that the percentage of people who had to be vaccinated away from their place of residence can be a satisfactory measure indicating inequalities in access to vaccinations between different regions (Barry et al. 2021), and that inadequate allocation of vaccination has led to additional inequalities in COVID-19 mortality (Chen 2022). Rankings visualising the level of risk of non-vaccination at the local level enable optimisation of population vaccination strategies (Bump 2021) and highlight the need for viable public health interventions to ensure equitable distribution of healthcare resources across populations.

Vaccines are the best way to prevent the effects of the COVID-19 pandemic. However, not all citizens are willing to be vaccinated. In many countries, discussions and dilemmas about vaccines, their safety and efficacy go beyond the orbit of scientific and medical knowledge, becoming an area particularly vulnerable to rumour and misinformation (Islam et al. 2021). The actions of anti-vaccine organisations (Kołłątaj et al. 2020) and negative public emotions around vaccines are geographically and socially diverse (Jarynowski, Skawina 2021).

In Poland, by 15.06.2021 (which corresponds to the timeframe adopted in the following analysis), 41% of Poles had received the first dose of the vaccine and 26% had been fully vaccinated. According to CBOS (Centre for Public Opinion Research), 26% of adult citizens declared that they had opted out of vaccination (CBOS 2021). Reasons for not vaccinating include lack of time (21%), undergoing COVID-19 (18%), postponing to a later date (17%), fear of Vaccine Adverse Events – VAE (16%) and poor health (10%). Approximately 10% of the unvaccinated declared difficulties in signing up for vaccination and 3% of those surveyed by CBOS reported that the inability to vaccinate was due to the lack of a vaccination centre near their place of residence (Omyła-Rudzka 2021). Demand-related reasons dominate among the distinguished motives for not receiving the vaccine, while supply barriers are indicated much less frequently. While the social unrest and controversy surrounding the COVID-19 vaccines have been a subject of numerous studies, supply barriers have rarely been analysed. In Poland, the supply-related aspect of this issue is practically not described. Therefore, in this study, we propose an approach to estimate what impact access barriers have had on vaccination rates, among others. The temporal scope of the analysis is limited to June 2021, when the access formula changed and vaccination could be received much more easily, in pharmacies and other places. It also seems that the first few months of the vaccination programme best describe the regional supply vulnerabilities of the system (e.g., its capacity), and thus could be a good indicator of vulnerability for other epidemiological threats in the future.

The public health interest dictates (Włodarczyk 2020) that failures in the planned National Vaccination Programme should be tracked, with particular attention paid to inequalities in access to vaccines (lack of vaccines or vaccination points), prioritisation of groups at risk of severe COVID-19 infection and its consequences, and reluctance to vaccinate. Social inequalities in the context of supply barriers are rarely addressed with regards to this issue. Barriers related to social controversy over the safety and efficacy of COVID-19 vaccines are much more frequently discussed.

Factors limiting access to specific health services can be explained by impediments classified into 5 domains: reachability, spatial accessibility, organisational accessibility, cost accessibility and acceptability (Kaczmarek et al. 2007). Thus, vaccination rates are influenced by the number of staff (primary health care providers, staff approving eligibility for vaccination, vaccination centres), and communication difficulties or specific views (Islam et al. 2021). In the analysis presented here, we pay particular attention to the role of supply (vaccination points and their staff) and its spatial distribution. The qualitative research identified a list of factors hindering access to health services (among others, in long-term care): limited supply (few providers), inadequate transport services, telecommunication barriers, financial unviability of some important services, and challenges in recruiting and retaining long-term care workers. Giving up some services or forms of care and replacing it with another choice (e.g., family care, opting out of vaccination) can be considered both as a cultural preference ("we will not put my parents in a nursing home" or "vaccination can be dangerous for me and my children") or a reaction to the poor quality of public services (Siconolfi et al. 2019), for example lack of trust in medical knowlegde. With regard to vaccination, the role of the family in the decision to vaccinate (so-called lay referral system) cannot be overlooked, which is partly a result of the communitarianism of making medical decisions in general, but also a response to the information chaos about vaccinations. Difficulties regarding signing up for vaccination and lack of accessibility constituted another variable impacting the establishment of anti-vaccination attitudes. However, it is worth noting that the barriers to accessing a physician, i.e., the inability to contact one or to commute to a GP's office, are *de facto* the inability to create a satisfactory patient-doctor relationship, which results in lower levels of trust in medical services. Trust in the relationship with a medical professional is a key ingredient for effective and quality care and a cornerstone in the fight against vaccination reluctance or disregard for medical advice. Relatively easy access and frequent contact with the physician can, in turn, be important in building an environment of responsibility for health at both the individual and local community level (as in the case of outbreaks or prevention of unnecessary consequences of infections).

In many countries, vaccination rates are higher in highly urbanised areas than in rural areas (Murthy et al. 2021). Variation in vaccination rates also depends on socioeconomic status, household composition and the proportion of people with disabilities, the health status of the population and the level of education. Interestingly, in the USA, vaccination rates are lower in regions with a higher proportion of mobile households (Barry et al. 2021). This shows that spatial barriers to vaccination are complex and overlap with other health inequalities (e.g., lack of access to physicians also means poorer access to medical knowledge). Limited access to doctors and distance from, for example, a vaccination point, lack of opportunity or high travel costs are factors that discourage vaccination and may, firstly, overlap with other social inequalities (low income) and secondly, increase the effect of other anti-vaccination arguments. Also in Poland, getting to the vaccination point, especially for at-risk groups such as seniors, was a matter of mobilising the personal resources of individuals, such as family or neighbours, who organised safe transport. This was mainly the case in the first period after the introduction of the vaccines (seniors were able to be vaccinated first, right after the representatives of the medical staff). For seniors, only 100 outpatient vaccination centres were launched nationwide.

Research also indicates that by supporting priority groups (seniors, professional groups), the discriminatory mechanism of geographical accessibility can be overcome (Jarynowski, Stochmal, Maciejewski 2020). However, this involves adequate planning of the access pathway (vaccination points) (Diesel 2020). In Poland, decisions on the vaccination access pathway were chaotic, and the vaccination information policy was also problematic.

Available analyses of determinants of vaccination rate (e.g., of adolescents in the US) showed, among other things, that 67% of differences in vaccination rates between urban and rural areas could be attributed to differences in characteristics at the district level (Tsai 2021). The most important variables referred to characteristics measuring access to primary health care, but also parental education and income level, race and quality of care (including influenza vaccination as a factor). The results indicate that the most important predictors of high vaccination rates include the number of primary care physicians (positive correlation) and car ownership (negative correlation). Socio-political factors such as education level and political views, including, for example, voting preferences and local political circles supporting the so-called anti-vaxxers, may also be important (Hornsey et al. 2020).

However, it is not only the nature of the region that influences vaccination rates. Many observers believe that promotional activities undertaken in the local media, implementing solutions based on local needs, working with local organisations and opinion leaders or working directly with groups of undecided citizens can successfully improve access to COVID-19 vaccines and remove barriers to access (Murthy et al. 2021). The ability to work with local partners who understand the nature of the community and the mechanisms that govern it can be key to the success of tackling health threats such as epidemics (Douthit et al. 2015: 611–620).

On the issue of access to vaccination, another point is worth addressing. Until April 2021, patients could only be vaccinated at special vaccination centres, but over time the number of sites and locations expanded to include clinics, pharmacies and shopping centres. The first patients were able to receive the vaccine without being deemed eligible by a physician at the beginning of July 2021 (eligibility for vaccination assessed by professionals other than physicians did not affect the baseline presented in the article). However, not all patients could be deemed eligible for vaccination by a pharmacist: in case of doubt in the assessment of a patient's health status (e.g., an elderly person, a person with chronic diseases, a person with a disability, a person at risk of vaccine adverse events), the pharmacist could refuse the vaccination and refer the patient to a physician. When it comes to the availability of vaccinations, there were therefore problems in terms of staff qualifications (fast-track training for pharmacists) as well as the level of trust in pharmacists, who up to now have not been involved in deciding if patient can be safely vaccinated (which in Poland is usually done by a physician) and the administration of vaccines (the "traditional" task of a nurse). The low popularity of pharmacies as vaccination sites can be evidenced by information from October 2021 posted on the website of the Supreme Pharmaceutical Chamber, stating that only 110,000 patients were vaccinated at 900 Pharmacy Vaccination Centres between April and October of that year (NIA 2021). The supply-side "trick" with pharmacies has run into the problem of the level of trust in the various health professions (in the early stages of vaccination), which could be considered as a limitation of access to medical procedures. Although in many situations the pharmacist is an important medical support and source of reliable information for patients, at the local level pharmacies as a vaccination provider have encountered a barrier of public trust.

Study purpose

While most analyses on the social determinants of vaccination rates focus on awareness aspects, related to the demand component (willingness or unwillingness to be vaccinated, doubts about vaccine safety, etc.) the present analysis aims to show the inequality of estimated vaccination rates in relation to the supply aspect. We sought to explain differences in vaccination rates using simple statistical methods (Jarynowski et al. 2014). In this article, the authors focus on assessing the impact of a constellation of selected factors on vaccination rates. The (supply-side) approach used is an attempt to complement the growing pool of research reports analysing the demand-side thread of pro- and anti-vaccination decisions among Polish citizens. The aim was to propose to complement and raise the validity of spatial factors, which may be of great importance in Poland in the context of meeting health needs. Limitations of the study include the limited time of analysis, the data are not exhaustive and not all variables were taken into account by the authors.

The data obtained can be used to classify at-risk areas and to propose cohesion policies at the district level. The implementation of comprehensive surveillance of vaccination rates should support timely, appropriate and effective action in the prevention and control of COVID-19 (Wojtyniak, Goryński 2020). The ability to optimally deploy resources in time and space is fundamental to efficient regional management at operational (district or municipality) and tactical (vaccination point) level, and it is to this aim that this analysis contributes. The intermediate objective is to propose further measures to optimise redistribution as a form of influence on the supply of health services in society, that is to say – in simple terms – what forms of support the most "lagging" (least vaccinated areas) can receive in a broader, not only vaccine-related, health perspective.

Material and Methods

Data and definition of variables. Some variables were selected for analysis, aggregated and available as of June 2021. The primary dataset of completed vaccinations in municipalities (MOH, Municipality Vaccinations 2021) required clarifying due to mis-recording of region identifiers by government programmers, but through collaboration with community activists/analysts (Jarynowski 2021) we were able to map the data. We took 380 districts as the unit of analysis. For this purpose, we calculated the average vaccination rate for each district (percentage of the population vaccinated with the full regimen) as of 15.06.2021 (*vacc* – the names of the variables defined here used further in the article are in italics and in brackets). Thus, vaccination rate is our dependent variable. The dataset was supplemented with available data on the uptake of at least one dose of vaccine and the size of the vaccinated population in different age categories. Analysing the material presented in the maps by some data analysts (Seweryn 2021; Kowalski 2021; Tarnowski 2021; Pilczyk 2021), we tried to describe the determinants of vaccination rates with district-level accuracy.

The independent variables were taken from the COVID-19 spread model (CSO 2021; Jarynowski et al. 2020; NEC 2019). These were:

- income (*Income*) normalised economy income data from 2019 (100 – average for Poland);
- forest density (*Forest_density*) – percentage of forest in 2018;
- population density (*density*) – in people/km2 in 2019;
- population size (*population_size*) – the number of people living in a given district in 2018;
- total industry revenue (*industry_revenue*) in 2018 in million PLN;
- occupational structure (*empl_agriculture*) – number of people working in the agricultural sector in 2014;
- number of people of post-productive age (*post-productive_age)* in 2019;
- betweenness mobility (*betweenness_mob*) – weighted betweenness centrality, calculated from the number of people registered at the tax office covering municipality A and working in municipality B (the place of registration of the employer’s activity). A key measure in social network analysis (Jarynowski et al. 2014), namely the estimated total number of people entering and leaving a district;
- results from the National Electoral Commission – support for the Law and Justice (PiS) party (*PiS_support*) in the European Parliament elections. Due to the lack of poll research with district accuracy, electoral preferences are a very good indicator of social attitudes in local communities.

The following were added to the model:

- variables determining virus burden in the immediate geographical environment (Rogalski 2021):
- *(size_COVID*) summed numbers of COVID-19 infections (from 04.03.2020 to 15.06.2021) and (*covid_death*) deaths from COVID-19 (24.11.2020 to 15.06.2021). It should be emphasised that details of deaths for each district from the first wave are not publicly available;
- excess mortality (*excess_mortality*) calculated as the number of deaths in 2020 divided by the average deaths in the five-year period (2015–2019);
- the number of consultations given in primary care in 2020 (*HealthcareAcc*) as an indicator of demand-driven accessibility to primary care. An indicator for 2019 (*HealthAcc_old*) was tested to exclude the effect of the pandemic, but the correlation between the two indicators is practically equal to 1, so no significant regional changes in access to medical advice were observed;
- the number of physicians working in health care per 10000 inhabitants (*HealthAcc_phys*) as an indicator of supply-side accessibility to health care;
- religious service attendance rate (*relig*) indicating the level of religiosity, with data specific to the provincial level (Cichomski et al. 2009).

It should be stressed that the selection of variables is analytical and not synthetic and consisted of selections based on preliminary correlation analyses. Some variables are only approximate. Thus, corporate profitability is a proxy for margin levels, which translates into the structure of production and positions in the supply chain (social contract). Forest density instead indirectly indicates the organisational structure in the district. It is noteworthy that some epidemiological variables such as the number of tests without additional information (such as how many tests are performed due to symptoms, outbreaks, legal requirements or screening) create more problems in terms of interpretation than they add value in explaining the relationship. The correlation between vaccination rates and their socioeconomic predictors (Walkowiak et al. 2022) at the population level is not well researched in contrast to the individual level by survey method. Therefore, the article is exploratory and hypothesis-generating.

Statistical analyses. Spatial exploratory and statistical techniques were used in the study (Kowalski et al. 2021; Bochenek et al. 2021). Pearson's coefficient was determined to obtain information on the relationship between variables in the form of correlation. Linear regression allows the impact of individual variables on the analysed quantity (vaccination rate) to be examined. The interpretation of this influence is based on the intrinsic parameters of the model (hence, we counted the percentage of the explained variability and proposed different models taking into account the Akaike criterion). In addition, the spatial clustering of DBSCAN (DeRidder et al. 2020) allows the automatic detection of clusters of districts.

Clustering of areas with similar vaccination rates is a well-known phenomenon used in epidemiological practice (Utazi et al. 2019). Exploring the distributions of vaccination rates allowed a heuristic setting of threshold values for classes of regions with different needs. Analyses were performed in the R environment and scripts and source data were deposited in a repository.

Optimisation issue. In addition, in view of the above analyses, we propose to divide the districts using the vaccination rate function into:

a) districts doing very well whose experience should serve as an example;
b) districts performing moderately that do not require additional investment;
c) below-average districts in need of local support (e.g., in individual municipalities);
d) vulnerable districts that require systematic assistance.

Results

Data exploration. The distribution of COVID-19 vaccinations in Poland in 2021 (as of 15.06.2021) varied widely [Fig. 1]. When analysing the level of vaccination coverage, it is easy to notice differences reflecting the division into urban and rural districts and the relationship with political preferences [Fig. 1, 2], which has already been noted in the analytical and medical community (Janota 2020). The clear variation in vaccination coverage between districts (average: 22.8% and standard deviation: 4.5) makes it possible to distinguish clusters and islands of highly vaccinated and poorly vaccinated regions (see subsection on the optimisation issue for a detailed interpretation).

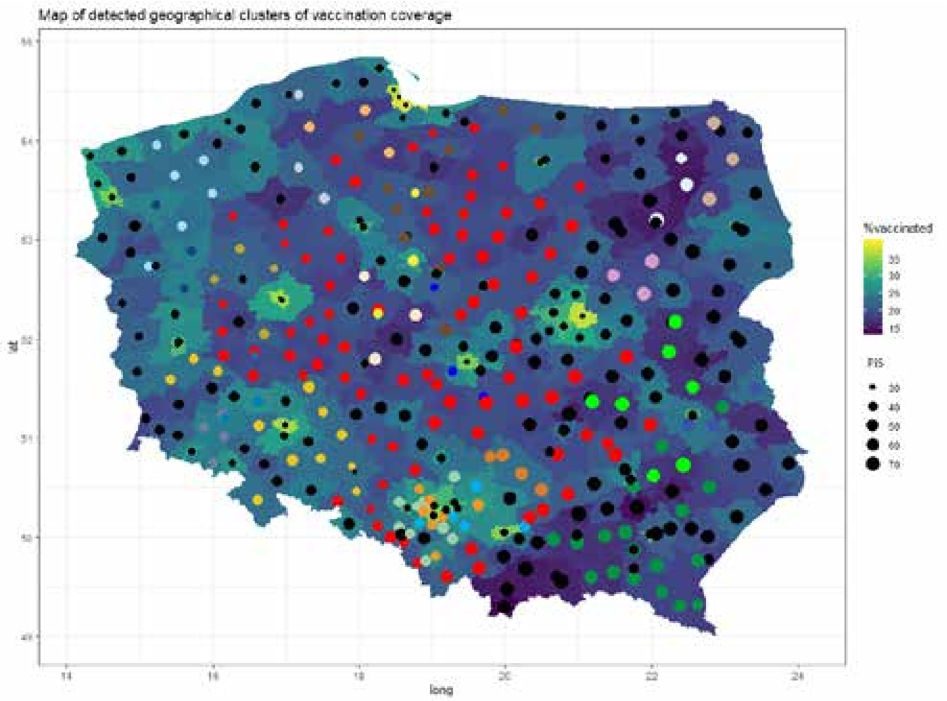
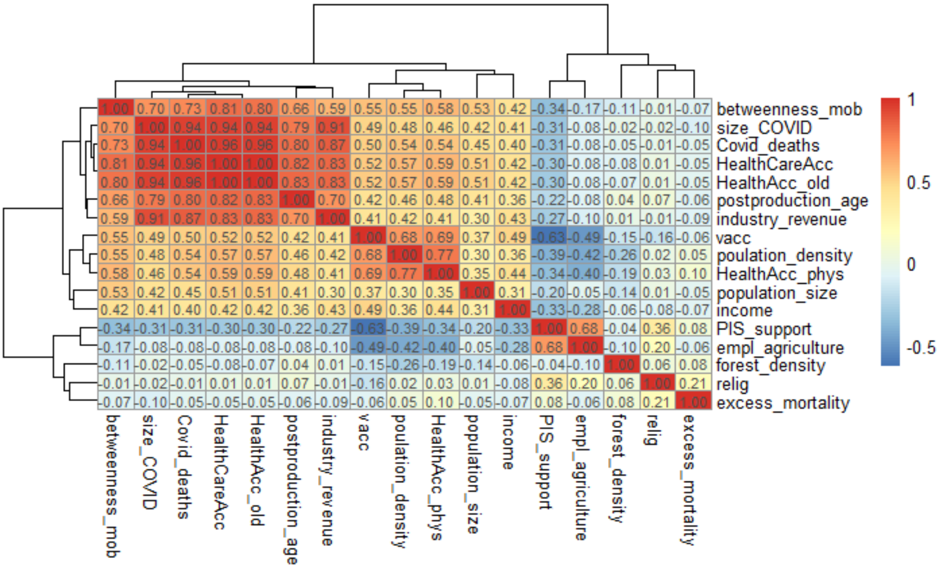


Figure 1. Percentage of residents vaccinated vs. support for Law and Justice (PiS) party at the district level in Poland. Method: Dbscan – spatial clustering at district level with an additional dimension – normalised percentage of vaccination coverage (map colour, see legend). The size of the circle points corresponds to the percentage of support for the Law and Justice party in the 2019 elections and the same colour of the circle is used to indicate the districts located in the same cluster (according to the level of vaccination coverage and geographical coordinates). Parameterisation eps=0.8, minimum number of districts in the cluster=3

Source: own study.

In the hierarchical arrangement [Fig. 2] of the correlations (dendrograms), a cluster of strongly positively correlated variables related to mobility, old age of the population, industrialisation, demand access to health care, number of COVID-19 cases, and COVID-19 deaths can be observed (upper left corner, Fig. 2). Another cluster consists of variables related to health service supply access, population size, population density, income and our most important variable, vaccination coverage (middle bands, Fig. 2). This may be an important rationale for the conclusion that access to vaccination based on the existing health service delivery network is an important criterion for vaccination coverage. The last cluster (bottom right corner, Fig. 2) refers to variables slightly negatively correlated with the first two clusters and is related to religiosity, excess deaths in 2020, support for Law and Justice, and environmental variables like forest density or agricultural employment.



	betweenness_mob	size_COVID	Covid_deaths	HealthCareAcc	HealthAcc_old	postproduction_age	industry_revenue	vacc	poulation_density	HealthAcc_phys	population_size	income	PIS_support	empl_agriculture	forest_density	relig	excess_mortality
betweenness_mob	1.00	0.70	0.73	0.81	0.80	0.66	0.59	0.55	0.55	0.58	0.53	0.42	-0.34	-0.17	-0.11	-0.01	-0.07
size_COVID	0.70	1.00	0.94	0.94	0.94	0.79	0.91	0.49	0.48	0.46	0.42	0.41	-0.31	-0.08	-0.02	-0.02	-0.10
Covid_deaths	0.73	0.94	1.00	0.96	0.96	0.80	0.87	0.50	0.54	0.54	0.45	0.40	-0.31	-0.08	-0.05	-0.01	-0.05
HealthCareAcc	0.81	0.94	0.96	1.00	1.00	0.82	0.83	0.52	0.57	0.59	0.51	0.42	-0.30	-0.08	-0.08	0.01	-0.05
HealthAcc_old	0.80	0.94	0.96	1.00	1.00	0.83	0.83	0.52	0.57	0.59	0.51	0.42	-0.30	-0.08	-0.07	0.01	-0.05
postproduction_age	0.66	0.79	0.80	0.82	0.83	1.00	0.70	0.42	0.46	0.48	0.41	0.36	-0.22	-0.08	0.04	0.07	-0.06
industry_revenue	0.59	0.91	0.87	0.83	0.83	0.70	1.00	0.41	0.42	0.41	0.30	0.43	-0.27	-0.10	0.01	-0.01	-0.09
vacc	0.55	0.49	0.50	0.52	0.52	0.42	0.41	1.00	0.68	0.69	0.37	0.49	-0.63	-0.49	-0.15	-0.16	-0.06
poulation_density	0.55	0.48	0.54	0.57	0.57	0.46	0.42	0.68	1.00	0.77	0.30	0.36	-0.39	-0.42	-0.26	0.02	0.05
HealthAcc_phys	0.58	0.46	0.54	0.59	0.59	0.48	0.41	0.69	0.77	1.00	0.35	0.44	-0.34	-0.40	-0.19	0.03	0.10
population_size	0.53	0.42	0.45	0.51	0.51	0.41	0.30	0.37	0.30	0.35	1.00	0.31	-0.20	-0.05	-0.14	0.01	-0.05
income	0.42	0.41	0.40	0.42	0.42	0.36	0.43	0.49	0.36	0.44	0.31	1.00	-0.33	-0.28	-0.06	-0.08	-0.07
PIS_support	-0.34	-0.31	-0.31	-0.30	-0.30	-0.22	-0.27	-0.63	-0.39	-0.34	-0.20	-0.33	1.00	0.68	-0.04	0.36	0.08
empl_agriculture	-0.17	-0.08	-0.08	-0.08	-0.08	-0.08	-0.10	-0.49	-0.42	-0.40	-0.05	-0.28	0.68	1.00	-0.10	0.20	-0.06
forest_density	-0.11	-0.02	-0.05	-0.08	-0.07	0.04	0.01	-0.15	-0.26	-0.19	-0.14	-0.06	-0.04	-0.10	1.00	0.06	0.08
relig	-0.01	-0.02	-0.01	0.01	0.01	0.07	-0.01	-0.16	0.02	0.03	0.01	-0.08	0.36	0.20	0.06	1.00	0.21
excess_mortality	-0.07	-0.10	-0.05	-0.05	-0.05	-0.06	-0.09	-0.06	0.05	0.10	-0.05	-0.07	0.08	-0.06	0.08	0.21	1.00

Figure 2. Pearson's correlation coefficient between the variables considered in the hierarchical analysis at the district level, where the most important variable (dependent) is vaccination rate (*vacc*) in relation to other variables such as those defining accessibility to health services: availability of physicians (*HealthAcc_phys*), access to health care facilities as measured by the number of medical consultations per capita in 2020 (*HealthCareAcc*) and in 2019 (*HealthAcc_old*) and other variables

Source: own study.

Levels of the demand access to health services in the pandemic year (2020) and the preceding year (2019) correlate at close to 1, meaning that spatial differences in health service use have not changed despite a completely different distribution of consultation types. This may be largely related to the execution of contracted services by the National Health Service (NFZ). The strong correlation between demand access to health services and the number of COVID-19 cases (0.94) and related deaths (0.96) as well as simultaneous negative correlation of these variables with excess deaths constitute an interesting observation. This can be explained in several ways. However, a conclusion arises that virtually nothing is known about the geographical distribution of SARS-CoV-2 infections, because we can predict the number of infections and deaths due to COVID-19 by looking mainly at the supply-side access to health care (Jarynowski, Belik 2022). This makes the negative correlation with excess deaths all the more indicative of a silent epidemic in areas with poorer access to health services.

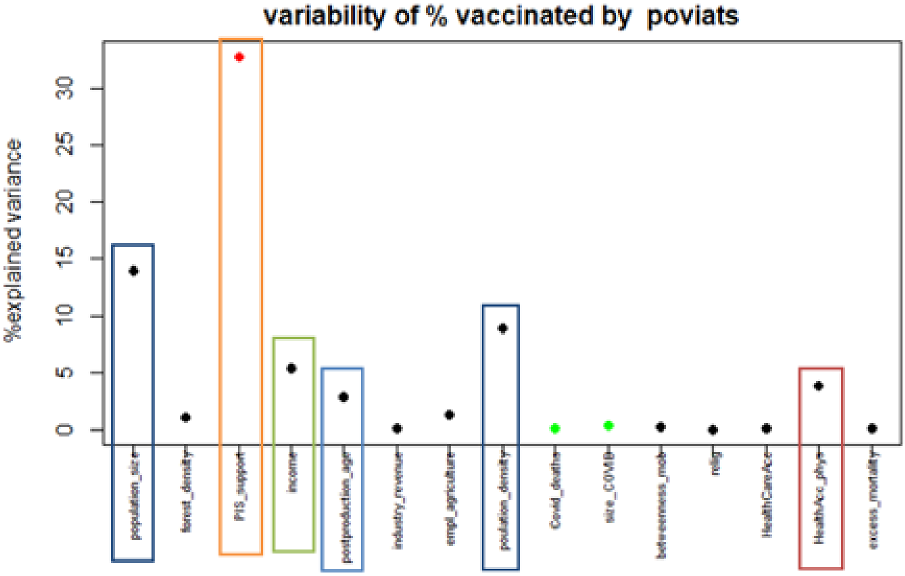


Figure 3. Linear multivariable regression predictive model of % vaccination coverage (the full model gives 75% of explained variance) on all tested non-co-linear variables (which are not a linear combination of other variables) at the district level. The % explained variance for each variable on the x-axis is shown on the y-axis. Coloured dots indicate epidemiological (green) and socio-political (red) and other (black) variables. Colour-coded boxes underline the significant predictors: demographic in blue for the urban dimension (dark) and age structure (light), economic in green, access to health care in red, political preferences in orange

Source: own study.

Predictive model of vaccination rates. Regression analysis of the full linear models [Fig. 3] indicates a small (borderline statistically significant) role of virus burden and religiosity. Excess deaths are not significant. Support for the Law and Justice party is a particularly significant predictor of vaccination dynamics (33%), which is indirectly related to the social structure of the electorate or the potential for resource management by local authorities. Population size (14%) and density (9%) also have a very strong influence on vaccination distribution, as most often vaccination points are located in densely populated areas (Elmachtoub, Grigas 2021). Income (6%) has a relatively high power to explain variation as well as the size of the post-working age population (2%). Supply-side access to health care (number of physicians) is also important (3%).

Table 1. Multivariate linear regression (variable selection according to Akaike's criterion) for two types of models (with and without interactions between variables). Dependent variable: the percentage of vaccination coverage in districts is significantly related to support for PiS: directly (model without interactions) and indirectly (model with interactions – taking into account intermediate variables, such as income, among others)

Model without interactions				**Model with interactions**		
Predictor	*cf.*	*CI (confidence interval)*	*p-value*	*cf.*	*CI (confidence interval)*	*p-value*
(Intercept)	22.0643	19.2966 – 24.8320	<0.001	-1.1243	-10.7156 – 8.4669	0.818
population_size	4.6227	-0.1247 – 9.3702	0.056	3.4938	-1.0001 – 7.9878	0.127
PIS_support	-0.1311	-0.1547 – -0.1075	<0.001	0.3378	0.1516 – 0.5239	<0.001
Income	0.0636	0.0365 – 0.0907	<0.001	0.3517	0.2369 – 0.4666	<0.001
industry_revenue	-0.0001	-0.0002 – 0.0000	0.109	-0.0001	-0.0002 – -0.0000	0.008
poulation_density	0.0028	0.0023 – 0.0033	<0.001	0.0026	0.0021 – 0.0031	<0.001
size_COVID	0.0001	-0.0000 – 0.0001	0.100	0.0001	0.0000 – 0.0001	0.026
betweenness_mob	0.0002	-0.0000 – 0.0004	0.108			
forest_density*post-production_age				-1.7585	-3.8080 – 0.2910	0.092
PIS_support * income				-0.0057	-0.0079 – -0.0035	<0.001
Observations	380			380		
R2	0.669			0.689		

Source: own study.

It should be emphasised that inequalities in access to vaccinations are most likely the effect of cumulative barriers, as in the case of the highlighted non-linear interaction of income with support for PIS or the interaction of forest density and size of the senior population (which, for example, may reflect elderly people living in hard-to-reach areas [Table 1]). The strongest explanatory variable for the percentage of vaccination remains, in both variants (models with and without interactions), support for Law and Justice. For every percentage point of support for the Law and Justice party, there is a 0.13% lower vaccination rate (after accounting for the impact of confounders such as population size and income on the correlation's deflation).

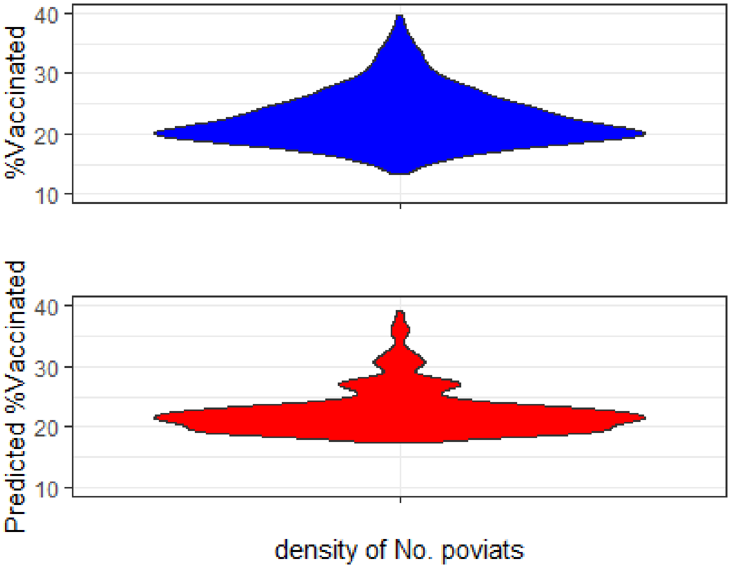


Figure 4. Histograms (violin plots) of the density of the district numbers for individual values of actual and model-predicted vaccination coverage without interactions [Table 1, left]

Source: own study.

The mode of vaccination rate is 20% and the median is 21.6% [Fig. 4]. Poviat districts (the most highly vaccinated ones located in the tail [Fig. 3]) shift the centre of gravity of the nationwide vaccination rate upwards due to their large populations.

Proposed classification of districts – an optimisation issue. We proposed to divide the districts into groups, using the average of the actual vaccination rate percentage and the predictive magnitude [Fig. 4, Table 1, left] with thresholds:

a) average vaccination rate >25%;
b) 20%< average vaccination rate <25%;
c) 18%< average vaccination rate <20%;
d) average vaccination rate <18%.

Including the resultant of the predictive model and the observed vaccination level distribution is a standard optimisation approach, as it reduces the significance of the error of poor selection of predictor variables and reduces randomness. It should be emphasised that the above distribution is ad hoc and other proposals may prove better in identifying issues.

Category D primarily includes clusters determined by the dbscan method [Fig. 1], and in particular:

- the southern borderlands of the Małopolskie and Podkarpackie voivodships, with particular emphasis on Podhale, and the Eastern Beskids;
- borderland of the Świętokrzyskie and Podkarpackie voivodships;
- borderland of the Mazowieckie and Podlaskie voivodships;
- borderland of the Mazowieckie and Lubelskie voivodeships.

Category C clusters can additionally be observed [Fig. 1]:

- in large areas outside the urban agglomerations of the broadly-considered eastern wall;
- on the border of the Łódzkie and Wielkopolskie regions;
- borderland of the Świętokrzyskie and Mazowieckie voivodships;
- southern Wielkopolska;
- south-west of the Pomorskie voivodeship;
- locally in other areas of the country.

Discussion

Our analysis is an attempt to add to our knowledge of the spatial relationships of vaccination rates in Poland in the light of the available empirical data (Włodarczyk 2020). The most important finding in the area of the social geography of vaccination coverage is the strong concentration of areas at risk for the fourth wave of the pandemic with a strong correlation with the level of (low) accessibility to health services in these areas. The results indicate that systemic (organisational) barriers may be an important factor in vaccination rates, indirectly influencing pro- or anti-vaccination attitudes, which are the focus of attention of the media, researchers and vaccination organisers. The still large unvaccinated population as of summer 2021 is not likely to be anti-vaccination, but rather made up of undecided or excluded citizens (Trojanowska et al. 2021; Bałandynowicz-Panfil 2021), especially in the C and D regions. The vaccination programme in peripheral areas accelerated (especially in at-risk groups there was a convergence to the Polish average [Walkowiak et al. 2022]) only at the beginning of 2022, i.e., when vaccination effectiveness against the Omicron variant was already declining (Jarynowski 2023). However, it is worth emphasising that the barriers to vaccination against COVID-19 reveal not only the low level of preparedness of the health system for the epidemic threat and its fragile resources on a big scale, but also the limited resourcefulness of the authorities and the timing of decisions.

The variation in vaccination rates at the local level is therefore, in our view, partly the result of supply and not just demand for vaccination. It is possible that barriers are constituted not only by the distance from the place of residence to the vaccination point, or the number of medical staff, but also the lack of cooperation with local opinion leaders (e.g., parish priests) and the lack of a medical culture favourable to vaccination. It is worth noting that the change from a denialist attitude to a decision to vaccinate can occur smoothly, as indicated by simulation results supported by Polish media data (Sobkowicz and Sobkowicz 2021), and therefore accessibility factors will be key to achieving the goals of the National Vaccination Programme.

It is worth noting that vaccination rates do not correlate with strictly measurable demand-driven access to health care (nor do they come out as significant in the model [Fig. 3, Table 1]). This may be partly due to agglomeration of data to the district level or to socio-economic demand for health services (Czekirda, Jarosz 2020). Other methods of approximating the availability of health services should be considered in the future. For example, the participation of private health services in vaccination campaigns may be a great relief for public services (in this context, it is worth recalling the lack of relationship between demand availability for NHS services and vaccination rates described in this analysis), especially as the strong correlation of demand availability with covid statistics may indicate that the public health service has borne the brunt of most of the impact of the pandemic. However, on the supply side of health services (staff size), there is a strong correlation (0.69) with vaccination rates and a significant variance explanation (5%). This is a further argument for the important role of the way in which vaccination campaigns are organised (supply) in explaining in-depth the spatial variation in vaccination rates, taking into account determinants other than citizens' willingness/acceptance of vaccination (demand) (Duszyński et al. 2021). It is conceivable that the main reason for the variation in vaccination rates may lie in the hands of local authorities and resource-limited health services, although the influence of demographic, socio-economic and ideological factors cannot be ignored. It is worth emphasising that resource allocation is a modifiable factor, much more so than successfully persuading opponents of vaccination, so it is worth exploiting opportunities to intervene.

Limitations. The article adopts simplified definitions of access to health care (Golinowska et al. 2011). Other measures should be considered in the future, such as the average travel time to the emergency medical team, the time to reach the nearest hospital/ambulatory care unit by public transport, etc. It is worth noting that religiosity (measured by surveys) does not have a statistically significant effect on vaccination rates [Fig. 3]. Perhaps using other indicators, e.g., the dominicantes index (Nowakowska 2011), would allow this relationship to be assessed, although it seems that it would still play a secondary role. The list of predictors could also be extended to include, for example, travel time by public transport/own transport to the nearest vaccination point, average household income and Gini coefficient, local election turnout, average education, unemployment rate, migration rates, etc.

The above study on the regional variation in COVID-19 vaccination rates suggests that conducting summer promotion and accessibility campaigns will significantly increase vaccination rates in areas lagging behind in vaccination coverage (Szymczyk 2016). It seems, therefore, that the main responsibility for the preparation of the campaign should lie with the regional government delegations, regional media and local governments (Jarynowski, Skawina 2021), which tend to be much more trusted than their central counterparts. On the other hand, substantive and financial support from the central administration is essential. Thus, significant resources and responsibilities should be directed to the poorest-performing districts (or municipalities) to prepare regional programmes aimed at increasing vaccination availability and to develop communication strategies.

Due to demographic, social and epidemiological variations in vaccination acceptance, as well as organisational capacities in the region, summer campaigns (before the potential autumn/winter wave in 2021/2022) should be redesigned at regional level (Halik, Kuszewski 2007). Unfortunately, by summer 2021, no nationwide seroprevalence studies with a spatial structure beyond individual regions such as the Silesian agglomeration (Zejda et al. 2021) had been published, so a precise determination of the herd immunity threshold (Jarynowski, Grabowski 2015) in the regions (further hampered by different vaccine protection levels for different SARS-CoV-2 variants) is not possible.

Summary

Variance explanation. A large part of the spatial variance in vaccination rates is accounted for by modifiable factors such as social attitudes and the resourcefulness of local organisers (33%), limited access to health care (3%) and hard-to-reach populations with special needs (2%) [Figure 3]. Less well-organised institutional and less accessible health care in less privileged regions may result in a large number of their populations not being reached with effective information and assistance in the vaccination process. The results suggest that an important variable explaining spatial variation in population vaccination rates is the way in which vaccination campaigns are organised (supply) and not just the willingness/acceptance to vaccinate (Rzymski et al. 2021a). Therefore, in addition to the continuation of educational programmes consisting of reliable information (Rzymski et al. 2021b) or marketing programmes (such as information campaigns and incentives, e.g., raffles), actions to facilitate accessibility to vaccination centres should also be strengthened in some locations.

Recommendations for districts at risk of exclusion. Districts in group A can be expected to continue to meet their targets. For districts C and D, investments should be made in rural peripheral areas (e.g., through better pricing of outreach and mobile teams, especially in villages already excluded). Mobile vaccination points should appear at points of concentration of the local population, e.g., under rural parish churches or during outdoor events such as harvest festivals. For D regions, there is a need for systematic actions combining communication campaigns with the use of different types of influence agents, e.g., religious organisations (such as the Catholic Church), NGOs (such as Rural Housewives' Circles) or officials (such as village leaders). Social welfare centres (GOPS and MOPS) should be supported so that they can assist families caring for dependents in the vaccination process, e.g., in forwarding requests for consent to the district courts if the patient is unable to give consent. Vaccinations can be offered by making phone calls to potential patients. It seems that the use of this form of intervention outside of D areas may even be counterproductive, as anti-vaccination movements particularly active in Poznań, Trójmiasto and Silesia will legally torpedo such actions (Jarynowski, Skawina 2021). Due to staff shortages particularly evident in D districts, long-term programmes aiming to fight the health access exclusion should be prioritised (Lachowski, Florek 2007). It is worth emphasising that this is a long-neglected section of the operation of the national social and health system (Drożdżak 2015). Additional incentives should be provided to support non-physicians medical practitioners (or those in training) who undertake work in rural D regions (Genowska et al. 2017; Charzyńska-Gula 2013). Another interesting solution would be to have summer internships or field trips of medical and health students with a focus on public health in areas C and D, aimed at health education (including promotion of COVID-19 vaccinations) among the local population. It may be worth relocating some staff experienced in population vaccination from regions A to D. Demand factors should take into account the socio-demographic profile of the region and be based on correct communication regarding vaccination with groups most at risk of infection or disease effects, e.g., seniors (Jarynowski, Skawina 2021; Bałabdynowicz-Panfil 2021; Skawina et al. 2016; Mastalerz-Migas et al. 2021), with a particular focus on rural populations (Seń et al. 2019). In summary, efforts to increase vaccination rates should be more often local, both in terms of demand and supply availability.

Acknowledgments

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Caring for the Health of Seniors as an Element of Health Policy in an Ageing Society

Demographic ageing is becoming a challenge in many areas of life, including public health policy. The increase in life expectancy leads to an increase in the number of diseases of old age, a decrease in the quality of life of older adults and difficulties in providing adequate care. Comorbidity, lack of proper knowledge, limited access to health promotion and prevention programmes are among the factors that lead to older adults not adopting health-promoting behaviours, which in turn leads to further deterioration of their condition. Social and health policies should equally provide complex care for seniors who experience deterioration of their condition, as well as activities to delay ageing and alleviate its consequences, which in return would enable them to live independently. Prevention and health promotion appear to be crucial elements of the aforementioned public policy.

The aim of the article is to present the objectives of health policy in relation to prevention and health promotion among older adults and to verify whether the health programmes implemented take seniors into account as their addressees. The article therefore presents the demographic situation in Poland and its consequences for the health care system, the ageing process in the context of health status, and the tasks and goals of health promotion and health prevention in the light of demographic development – the overview takes into account the scientific and factual situation in this area. The last part presents the results of an empirical analysis of national health policy programmes with regard to the criterion of age.

Keywords: demography, older adults, health policy programs, prevention,
health promotion

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Introduction – the demographic situation in Poland

According to the Central Statistical Office data from the National Population and Housing Census 2021, the population of Poland on 31 March 2021 was 38.1798 million. Compared to the 2011 Census, the structure of the population by economic age group has changed significantly – both the percentage of the population in the pre-working age group (0–17 years) has decreased – from 18.7% in 2011 to 18.2% in 2021, as well as in the productive age group (18–59/64 years) – from 64.4% to 60%, while the proportion of people in the post-productive age group (60/65 years and over) increased significantly – from 16.9% to 21.8% (CSO 2022).

The demographic forecast for Poland indicates that its population will continuously grow older, with a simultaneous depopulation of the country – it is estimated that Poland's population will reach 34 million in 2050. In 2030, Poland's population aged 60+ will increase by almost 11% compared to 2021, reaching 10.8 million, and in 2050 will increase by almost 41% compared to 2021, reaching 13.7 million in this age group. This means that in 2050, people aged 60 and over will comprise 40.4% of the total population (Kamińska-Gawryluk 2022). According to the above-mentioned forecast, the structure within the elderly group will also change in 2050, as there will be a decrease in the number of people aged 60–64 (from 26.3% in 2021 to 19% in 2050), 65–69 (from 25.6% to 21%) and 70–74 (from 20.4% to 19%). In contrast, older groups of seniors will see a rise in numbers – in the 75–79 age group (from 11% in 2021 to 15.2% in 2050), in the 80–84 age group (from 8.5% to 10.7%) and in the 85+ age group, where the largest increase is projected (from 8.2% to 15.1%) (Kamińska-Gawryluk 2022).

In contrast, the 2014 forecast illustrates the following trends among the two younger groups: 0–14 and 15–64 age groups (Szałtys 2014)[2]. It estimates that the population of 0–14 year-olds will decrease by 1.65 million by 2050 to reach 4.1 million in 2050, while the 15–64 age group will decrease by 8.3 million, from 26.8 million to 18.5 million.

One indicator is also worth mentioning in this brief analysis – the old-age dependency ratio. It represents the number of people aged 65+ per 100 people aged 15–64. A dynamic increase in this indicator has been noticeable since 2011 (from 19.4 in 2011 to 28.9 in 2021). Previously, it was at a relatively stable level (18.9–19) (Kamińska-Gawryluk 2022).

The final two measures to which reference is warranted include life expectancy and health expectancy (or healthy life years – HLY). The former measure is one of the most popular simple synthetic measures used to assess the overall health of

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[2] This forecast by the Central Statistical Office was based on biological, not economic, age groups, hence the differences in age ranges compared to the 2021 forecast.

a population, while the latter is a composite measure. In order to calculate it, the entire lifespan is divided into years lived in good health and those lived in ill health. Therefore, what is the average life expectancy? According to the *PolSenior 2* research report, in 2018, women aged 60+ in Poland had an average of 24.2 years of life ahead of them, whereas men could expect to enjoy a further 19.1 years (Wojtyniak 2021; Kamińska-Gawryluk 2022), i.e., 1.6 and 2.9 years fewer, respectively, than their peers in the European Union (Wojtyniak 2021). Analysis of the most recent data shows that, from 2019 onwards, the average life expectancy in Poland has started to decrease – in 2021 it was 22.4 years for women (24.2 in 2019) and 17.3 years for men (19.3 in 2019) (Kamińska-Gawryluk 2022). Regarding HLY among people aged 65 and more, it was 8.2 years for men and 8.8 years for women in 2018 (Wojtyniak 2021).

As demographic analyses show, the growing interest in the issues of old age, ageing and older people is well founded. Ageing is a subject of research and a driving force for the development of many scientific disciplines, but also an area of planning for all state policies – economic, social and health-related. As written by Stanisława Golinowska:

> In economic policy, efforts are made to seek ways of boosting economic dynamism despite the impact of demographic factors that weaken overall labour productivity. In social policy, considerations revolve around methods of ensuring financial security for the elderly population, which allow for the preservation of intergenerational financial equilibrium within redistribution systems. In healthcare policy, the analysis focuses on the possibilities of providing healthcare to the elderly population whose health condition naturally deteriorates, as well as mitigating the ageing process to enable older individuals to maintain their functionality and independence for as long as possible (Golinowska 2016).

Older people are living longer, but their quality of life is significantly reduced in their declining years. In addition, the old-age dependency ratio is increasing, which, coupled with their growing frailty and dependence, leads to a range of negative psychosocial and economic consequences. Therefore, issues related to actions that enhance health resources of older age should become a significant area of the country's healthcare policy. The responsibility of the state should not only involve providing medical care in times of illness but also the undertaking of actions aimed at delaying the ageing process and mitigating its consequences to enable older individuals to maintain their independence for as long as possible.

The concern for the health of the elderly within the framework of state health policy addressed in the article is justified in the light of the data presented on the demographic situation in Poland and its consequences for the health of the elderly. The article has two objectives. First, to illustrate the tasks of health policy in the area of prevention and health promotion with regard to older people. This analysis will be presented from a scientific perspective, taking into account the concepts of ageing processes, and in the light of documents defining the strategic and operational goals of health programmes as well as the entities and units responsible for their creation and implementation. Secondly, the aim of the article is to examine what the implementation of health programmes looks like in practice in the light of the tasks and objectives assumed in the health policy of an ageing society, based on an analysis of nationwide health programmes. The analysis of the types of health problems addressed by the programmes and the number of programmes targeting the elderly made it possible to verify the main hypothesis of the article, to wit, that nationwide health programmes do not address seniors sufficiently.

Ageing processes and health

Ageing is a process of regressive changes characterised by individual course (Ogińska-Bulik, Zadworna-Cieślak and Rogala 2015) and old age is defined as the declining phase of the life cycle, leading to death (Kijak and Szarota 2013). The individual course of the ageing process is a combination of genetics, living environment, personality factors and life experiences. **In the physical dimension**, ageing is characterised by changes such as: weakening of physical and mental fitness, decreased physical capacity and strength, balance disorders, motor coordination, falls, more frequent fatigue, heaviness and aversion to active physical efforts, loss of muscle mass (sarcopenia) and loss of bone mass (Kostka and Koziarska-Rościszewska 2009; Kubińska and Pańczuk 2019). In addition, insomnia, headaches, joint pain, back pain, illness, disability, i.e., loss of health and fitness, may occur (Kubinska and Panczuk 2019). **In the psychosocial dimension**, ageing processes are associated with the transformation of social roles (exclusion from professional, social, societal, and family life), loss of loved ones, deterioration of financial situation, loss of independence and sense of self-worth (Kijak and Szarota 2013; Kubińska and Pańczuk 2019). Both of these dimensions are interdependent, which is clearly illustrated by the three types of ageing (Renn-Zurek 2021). **Successful ageing** is a process in which external factors play a positive role. It is associated with a high degree of physical and mental fitness, a low risk of developing chronic disorders and, consequently, an active life. Socio-economic factors such as higher education, having a partner, a better financial situation, a proper lifestyle and having support are conducive to successful ageing. Positive attitudes to life (satisfaction with life, control over life, low health care demands, positive self-assessment of health status) play an important role. The last group consists of physical conditions – absence of chronic diseases, high initial physical fitness and normal body weight. **Normal ageing** is an ageing process in which some deficits are perceived, but no clear pathology is present. External factors can exacerbate the negative consequences associated with this type of ageing. Such factors include: loss of control over one's life, reduction in independence, inadequate levels of social support, death of loved ones, reduction or weakness in fulfilling social roles and maladaptation to old age. **Impaired ageing** is the least desirable course of the ageing process, characterised by so-called multimorbidity, running in a pathological manner. The most common comorbidities in older people include joint and spinal disorders, hypertension, ischaemic heart disease, diabetes, chronic lung and eye diseases, atherosclerosis and mental disorders associated with the ageing process. Among the most significant risk factors are genetic and environmental factors: inappropriate lifestyle, poor diet, harmful working conditions, pollution in a place of residence, and past illnesses and injuries.

Probably everyone would like to grow old successfully, but most people experience a loss of health as they age. Older people suffer from multimorbidity, (co-morbidities of a chronic nature), which requires complex medical care. In 2021, 98 million consultations were provided as part of outpatient healthcare to people aged 65 years and over, accounting for almost 31% of total consultations provided (Kamińska-Gawryluk 2022). In primary care this was 59.5 million consultations, in specialised care 33.5 million, and in dental care the number of consultations provided to people aged 65 and over amounted to 5 million.

The *PolSenior 2* report indicates the main health problems reported by people in the 65+ age group to primary care physicians (PCPs) and GPs and describes the main reasons for hospitalisation in 2018 (Kostka 2021). The 10 most common reasons for a visit to PCPs and GPs included cardiovascular disease, hypertensive disease, osteoarticular disease, diabetes, ischaemic heart disease, chronic gastrointestinal diseases, peripheral nervous system diseases, chronic respiratory diseases, thyroid diseases, and cancer.

People aged 60 and over constituted nearly half of all hospital admissions in 2018 (Kostka 2021). Older people were most often hospitalised due to cardiovascular diseases – this comprised ¼ of all hospitalisations in this age group (with slightly higher prevalence among men than women). The second most common reason for hospitalisation was malignant and benign neoplasms, accounting for 16% of hospital admissions in 2018 (17.9% for men and 14.4% for women). Other causes of hospitalisation mentioned by the authors of the report include mention eye diseases (mainly cataracts), diseases of the respiratory, digestive and genitourinary systems, trauma, and poisonings.

The co-occurrence of several conditions requires specialised care of multiple physicians, who treat a condition only from their area of expertise and often lack insight into the elderly patient's overall health. Geriatric care is becoming an effective solution. In 2021, there were 156 geriatric outpatient clinics in Poland, with the highest availability per number of older people in the Łódzkie and Śląskie voivodeships, and the lowest in the Warmińsko-Mazurskie Voivodeship. A total of 73.1 thousand consultations were provided in these clinics in 2021 (Kamińska-Gawryluk 2022). In 2021, there were 51 geriatric wards in Poland with a total of 1,048 beds, where 21.3 thousand people were treated during the year (Kamińska-Gawryluk 2022). The largest number – 12 geriatric wards – was in the Śląskie Voivodeship.

Ageing inevitably leads to death. Analysis of data on deaths among the elderly shows that for years the leading causes of death have been cardiovascular disease and cancer (Kamińska-Gawryluk 2022). Due to cardiovascular diseases, 37.6% of people aged 60+ died in 2021 (34.8% in the general population), more often women (41.2%; a 33.7% mortality rate among men). 19.6% of the elderly population died from cancer (similar to the general population), more often men (21.6%) than women (17.6%). In 2019, older people were most likely to die from tracheal, bronchial and lung cancers (19,923 people in total), colorectal cancer (7032 people), urinary tract cancers (6313 people) and female genital cancers (5685 people) (*Demographic Yearbook 2021*, 2021). It is worth noting that the number of deaths resulting from colorectal cancer, urinary tract malignancies and female genital malignancies increases with age. These data are relevant to the development of prevention and health programmes targeting older people.

Since 2020, a new cause of death, COVID-19, has been observed. The epidemic is more likely to threaten the elderly, which is reflected in the death statistics – in 2021, 18.6% of people over 60 years of age died from coronavirus (17.9% in the general population), while the death rate was 8.6 and 2.4 respectively.

Health deteriorates with age and an ageing population is becoming a challenge for the health system. It therefore makes sense – in addition to treatment-oriented remedial actions – to take action to strengthen health, promote individual responsibility for it and to encourage research aimed at early detection of disease.

Tasks and objectives of health promotion and prevention in the context of demographic challenges – a scientific perspective

"Prevention is better than cure", the famous words of Hippocrates emphasise the importance of taking action directed at avoiding illness before it occurs. The dominance of the biomedical model of health and disease has led to the fact that for many decades health issues have been sidelined, prioritising disease and its effective treatment only. This model is still dominant in medicine, hence resulting in ambivalence towards health promotion (Puchalski 2011). A turning point in broadening the perspective on human health was a report by Marc Lalonde in 1974, in which he described the concept of "health fields", emphasising the influence of environmental and lifestyle factors on the health of the population and attributing much less importance to genetic factors and health services than was commonly assumed. However, this concept, now seen as oversimplified, has influenced a shift in health policies and allowed the development of new models of health – including the socioecological model, which makes the category of health a central concept in the considerations and actions taken by and for individuals and communities.

Health as described in the concept proposed by the World Health Organization (WHO) is considered:

- normative – it is a value through which individuals and groups can achieve their goals, satisfy their needs, and modify their living environment;
- tangible – it is a resource (a type of good) through which social development and quality of life are made possible;
- instrumental – it is a tool used in everyday life; it is not life's purpose;
- evaluative – it is a positive category emphasising the benefits of "being healthy" (Woynarowska 2017).

In the context of demographic challenges, health understood in this way goes beyond the framework of medical institutions and activities, instead becoming the subject of socio-health policies (Golinowska 2016).

Attempts to reorient health and consider it a central category contributed to the development of the idea of health promotion, which in the Ottawa Charter classical study ("Ottawa Charter for Health Promotion" 1986) was defined as "a process that enables people to control and enhance their own health", thus becoming "not only a responsibility of the health sector, but extending beyond lifestyles to well-being". Health, in turn, was defined as "a resource of everyday life, not its goal; health is a positive concept emphasising social and personal resources as well as physical potential" ("Ottawa Charter for Health Promotion" 1986). The Ottawa Charter identified six basic lines of action in the area of health: 1) defining a national health policy, 2) creating a health supportive environment, 3) enhancing social action, 4) developing personal skills of individuals, 5) reorienting health services from treatment to prevention and education, 6) long-term strategy placing care and the holistic perspective as well as ecology at the centre ("Ottawa Charter for Health Promotion" 1986).

Health promotion activities are aimed at the general public, so no group should be left out of their planning and implementation. Often, however, specific programmes are targeted at a narrowly defined audience (children, blue-collar workers, etc.) as there are legitimate reasons (health, economic, psychosocial) for doing so.

In that case, what is the situation of older people as recipients of health promotion and prevention programmes? Is it at all reasonable to talk about the issue and take action of this nature in a group of people in which – as shown above in the analysis of the health of the elderly – the incidence of diseases and limitations is widespread, and multimorbidity and dependence increase with age? To put it bluntly, is it not too late for prevention and health promotion among those who have reached the age of 60 and over? Can such measures maintain the current state of health of older people or even improve it? Can discrimination against older people be found in such programmes?

Until 1990, many European countries perceived older people as not amenable to lifestyle change, so health promotion among them was unwarranted and they were neglected in such programmes (Golinowska et al. 2016; Heszen-Celińska and Sęk 2022). Today, many studies confirm that older people are inclined to keep themselves healthy, both physically and mentally, by remaining active and maintaining social contacts (European Union 2019). In addition, older people, precisely because of increasing ailments and limitations, begin to attach more importance to their own health in old age; it constitutes an autotelic value for them. They thus become more receptive to health education and to taking specific actions to maintain or improve their own health (Golinowska 2016). Targeting them with health-promoting content and activities therefore seems to be justified and necessary. However, the intrinsic diversity of the elderly population in terms of, for example, health status and related limitations should be taken into account, which is important when defining promotion and prevention goals and tasks. As Golinowska writes, "health promotion addressed to older people is, to some extent, an alternative to programmes focused on increasing financing of costly treatment services for an ageing population" (Golinowska 2016: 33). Elsewhere, the author also draws attention to the fact that many activities promoting health and health-related activities among the elderly focus on younger seniors, while in the group of older seniors (85+) the focus is placed on the appropriate level of medical care (infrastructure, accessibility, services) and satisfactory relations with medical staff, and to a much lesser extent on health behaviours (Golinowska et al. 2016).

It should also be remembered that older people face not only health problems, but also material (low income) or psychosocial problems (loneliness and isolation), so effective strategies should involve the cooperation of many professionals and institutions (psychologists, sociologists, physicians, health educators, nurses; medical institutions, NGOs, state institutions, informal groups), and should emphasise non-medical determinants of health and be more individualised.

The following strategic objectives of health promotion for older people are distinguished: maintaining and enhancing functional capacity, maintaining and enhancing self-care, stimulating an individual's social network, enhancing social participation and integration (Golinowska et al. 2016). The first goal refers to the physical health dimension and the remaining to the psychosocial dimension. At the operational level, health promotion programmes take into account (Golinowska 2016):

- the functional criterion – the action is intended to perform a specific function:

  - the informative function is carried out through the production and dissemination of health information on health and risks of specific diseases;
  - the educational function – its purpose is health education, the aim of which is to raise awareness among older people by providing knowledge about correct and incorrect health behaviour and its consequences, and about risk factors;
  - the diagnostic (and partly informative) function – realised through screening, the results of which serve as information not only for those concerned (the patients), but above all for those responsible for shaping health policies;
  - the preventive function carried out as part of primary prevention, taking the form of information, prevention activities, promoting correct lifestyles, aimed at preventing a specific disease;
  - the socio-technical function realised through advocacy, i.e., raising the value of health at the individual and societal level by influencing society;
- the place of health promotion criterion – refers to the place in the physical or environmental sense where activities of a health-promoting and health-protecting nature are undertaken (place of residence, workplace, home, care units [hospitals, nursing homes], media, community);
- the criterion for the type of activities that are indicated as conducive to health (physical activity, good nutrition, vaccination, avoidance of health risks associated with smoking, alcohol consumption, loneliness, among others; mental health care, sexual health).

The shaping of health programmes in Poland is the responsibility of the relevant ministries and the local government units. So what does the right to health look like in the light of strategic documents? These issues will be discussed in the next part of the article.

Health policy and health programmes in the light of strategic documents

The right to health and its protection is guaranteed to every person under international documents (Declaration of Human Rights) and national documents (Constitution of the Republic of Poland of 2 April 1997). Four categories of persons have the right to special care: children, pregnant women, persons with disabilities and the elderly. An elderly person in Poland is anyone over 60 years of age (Rada Ministrów [Council of Ministers] 2015a). Precise guidelines for the implementation of tasks related to the protection of citizens' health are contained in other, specific laws. They indicate the entities, tasks, responsibilities, monitoring of results and also the manner and sources of financing of activities. One such key document is the Act of 27 August 2004 concerning the Public Funding of Healthcare (Rada Ministrów [Council of Ministers] 2004). The Act sets out the tasks regarding health programmes, prevention and health promotion for two state entities with legal personality – the National Health Fund (NHF) and the Agency for Health Technology Assessment and Tariff System (AHTATS). The National Health Fund is responsible for health programmes (in terms of their development, implementation, realisation, financing and monitoring), pilot programmes (in terms of their implementation, realisation, financing and evaluation), performs tasks within the framework of health policy programmes and is the body responsible for health information and promotion activities. AHTATS is responsible for the preparation of materials necessary for the development of maps of health needs and is the body producing opinions on draft health policy programmes prepared at the ministerial level or below.

Another important document that defines the tasks and the rules for their financing and describes institutions involved in them is the Public Health Act of 2015 (Rada Ministrów [Council of Ministers] 2015b). Public health tasks are described in Article 2 of the cited Act and include, among others, monitoring and evaluation of the health status of the population; health education adapted to the needs of different population groups, in particular children, adolescents and the elderly; health promotion; prevention of diseases; activities aimed at elimination of risks; analysis of the health services provided; carrying out scientific activities; development of human resources; reduction of health inequalities, and activities in the area of physical activity (Rada Ministrów [Council of Ministers] 2015b).

In order to effectively implement public health policies, the Ministry of Health periodically approves the National Health Plan. The National Health Plan (NHP) for the period 2021–2025 is currently in force (Rada Ministrów [Council of Ministers] 2021a). According to the document, the aim of the NHP is to increase the number of healthy life years (HLY) and also to reduce social inequalities in health. The latter objective in particular appears to be extremely important in the context of the considerations made so far. The operational objectives are aimed at dealing with the health impacts of the COVID-19 pandemic and include: prevention of obesity; prevention of addiction; promotion of mental health; environmental health and infectious diseases; and demographic challenges (Rada Ministrów [Council of Ministers] 2021a).

At the local government level, there are many prevention and health promotion activities resulting from the above-mentioned provisions of national laws, but many initiatives are own tasks resulting from the provisions of relevant local laws, e.g., the Act on Commune Self-Government, the Act on County Self-Government and the Act on Voivodship Self-Government.

In view of the general situation of older people, actions aimed at strengthening and maintaining health should be interdisciplinary and take into account not only the category of health in a strict sense, but also other actions that indirectly affect the well-being of older people. Therefore, the following documents should be mentioned. The first of these is “Social Policy for Older Persons 2030: Safety – Participation – Solidarity” (Rada Ministrów [Council of Ministers] 2018b). As the document states, “the goal of social policy towards older people is to improve the quality of life of seniors by enabling them to remain independent and active for as long as possible and to ensure safety; the activities undertaken should take into account the recommendations of the World Health Organization and the activities of the European Commission on healthy and active ageing” (Rada Ministrów [Council of Ministers] 2018b). The document identifies seven main areas that take into account actions for older people, including strengthening positive attitudes towards old age, actions aimed at the inclusion of older people, creating conditions that enable them to realise their potential, increasing their physical safety by countering violence; intergenerational integration; educational actions and health promotion; and disease prevention as well as access to diagnosis, treatment and rehabilitation (area IV) (Rada Ministrów [Council of Ministers] 2018b). Among the specific tasks in the latter area, the most important are: strengthening individual responsibility for health, its promotion, disease prevention and strengthening health-promoting attitudes among the elderly as well as access to health care services, including rehabilitation and prevention of physical and mental health disorders (Rada Ministrów [Council of Ministers] 2018b). The second document is the “Active+” Multiannual Programme for Older Persons for 2021–2025 (Rada Ministrów [Council of Ministers] 2020), which aims to increase the participation of older people in all areas of social life. The priority areas include: social participation, social activity, digital inclusion and preparing for old age. The last programme is the “Senior+” multi-annual programme for 2021–2025, which aims to develop a network of “Senior+” Day Care Centres and “Senior+” Clubs and support economically inactive people over 60 by enabling them to participate in various social, physical, educational, cultural and caring activities within the framework of the aforementioned facilities (Rada Ministrów [Council of Ministers] 2021b).

As can be seen from the aforementioned review of scientific literature and strategic programmes, the health of the elderly appears to be one of the most important values towards which multidirectional, interdisciplinary measures are taken to enhance the well-being of individuals and the population as a whole. Health is also a central category for many strategic documents of the state, determining the directions of specific policies (especially health and social policies).

Results of the analysis of health programmes in the context of an ageing population

Methodological note

The following are the results of an analysis of nationwide health policy programmes, health programmes, prevention programmes and pilot programmes from 2015 to the present. A search was performed using online resources by entering the keywords "health programme" and "prevention programme" into the Google search engine in the Chrome browser, version 112.0.5615.138. The obtained records were then searched for documents meeting the predefined inclusion criteria: 1) the nationwide nature of the programme, 2) the start of the programme no earlier than 2015, 3) the availability of programme documentation allowing verification of the objective, target group and analysis of activities. Out of an initial pool of approximately 150 programmes found, 40 national programmes from 2015 onwards meeting the criteria listed above were finally analysed. Table 1 details them in a chronological order – title, period of implementation and whether the programme included older people. The analysis carried out took into account the health problem, the purpose of the programmes, the way they were implemented, their duration and addressees as well as the inclusion criteria. The analysis had two objectives. First, to examine which health problems the programmes addressed in order to see what proportion of them included conditions suffered by older people. Second, the aim was to see what proportion of all programmes constituted those that could benefit older people. In this case, the intention was to verify whether the programmes applied exclusionary age criteria.

Formal characteristics of programmes in the light of definitions

A health policy programme constitutes "planned, broad health care activities that are effective, safe and justified" (Ministerstwo Zdrowia [Ministry of Health] 2023). The aim of such programmes is usually to detect and address a specific health need and, consequently, to improve the health status of the target group. **Health programmes** face similar aims and objectives. The difference between them concerns the type of entity that is responsible for them – in the case of health policy programmes, it is the Ministry of Health and local government units, while in the second case the responsible entity is the National Health Fund. **Pilot programmes** test new health solutions before they are implemented as part of larger programmes or strategies. A **prevention programme** is an action aimed at preventing the occurrence of a health problem, but considering the levels of prevention, programmes are also created to minimise the effects of diseases and dysfunctions that have already occurred.

Table 1. National health policy programmes, health programmes and pilot programmes since 2015

PROGRAMME TITLE	PERIOD OF IMPLEMENTATION (ascending)	TARGET GROUP – OLDER PEOPLE (+/-)
Ensuring Poland's self-sufficiency in blood and blood components for 2015–2020	2015–2020	(+) the programme did not specify an upper age limit for the donor
National programme to reduce mortality from chronic lung diseases through the establishment of non-invasive mechanical ventilation rooms 2016–2019	2016–2019	(+)
Monitoring the oral health status of the Polish population 2016–2020	2016–2020	(+) older people were included as a 65–74 age category and were subject to the 2019 survey (962 respondents in total)
National antibiotic surveillance programme 2016–2020	2016–2020	(+)
Programme for the prevention of depression in Poland 2016–2020	2016–2020	(+)
Prevention programme for early detection of rheumatoid arthritis	2016–2023	(+/-) discriminatory age criteria
Health policy programme to implement the "Za życiem" comprehensive support programme for families for 2017–2021	2017–2021	(-)
POLKARD Cardiovascular Disease Prevention and Treatment Programme 2017–2021	2017–2021	(+)
ABCDE of nevus self-monitoring – nationwide skin cancer prevention programme	2017–2023	(+/-) discriminatory age and other criteria (labour force participation)
National Programme for the Prevention of Cerebrovascular Diseases (ICD10: I60–I69)	2017–2023	(+/-) discriminatory age criteria
Osteoporotic fracture prevention coordination programme	2017–2023	(+/-) discriminatory age criteria
Prevention programme for tick-borne diseases	2017–2023	(+)
Improving access to dental services for children and young people in schools in 2018	2018	(-)

PROGRAMME TITLE	PERIOD OF IMPLEMENTATION (ascending)	TARGET GROUP – OLDER PEOPLE (+/-)
Government programme for comprehensive intrauterine therapy in the prevention of sequelae and complications of developmental defects and diseases of the unborn child – as part of improving the health of unborn children and newborns for 2018–2023	2018–2023	(-)
Breast cancer prevention programme	2018 to date*	(+/-) discriminatory age criteria
Cervical cancer prevention programme	2018 to date*	(+/-) discriminatory age criteria
Prenatal screening programme	2018 to date*	(-)
Smoking-related diseases prevention programme (including COPD)	2018 to date*	(+/-) discriminatory age criteria
Orthodontic care of children with congenital defects of the craniofacial region	2018 to date*	(-)
Treatment of children in a coma (ICD-10 principal diagnosis: R40.2)	2018 to date*	(-)
Treatment of adult patients in a coma (ICD-10 principal diagnosis: R40.2)	2018 to date*	(+)
Postnatal depression prevention programme	2018–2023	(-)
Head and Neck Cancer Prevention and Early Detection Programme	2018–2023	(+/-) discriminatory age criteria
National programme for the prevention of arteriosclerosis and heart disease (KORDIAN)	2019–2022	(+)
Pilot programme for prevention of liver cancer through early detection of chronic HCV and HBV infections in adults in Poland	2019–2023	(+)
National chronic back pain prevention programme	2019–2023	(-!) discriminatory criteria (labour force participation)
Tuberculosis prevention programme	From 2019 to date**	(+)
National programme for the prevention of lymphoedema after breast cancer treatment	2020–2023	(-!) discriminatory criteria (labour force participation)
Prevention of colorectal cancer	2020–2030	(+/-) discriminatory age criteria
E-addiction treatment in children – a pilot	2021–2023	(-)

Government programme for comprehensive protection of procreative health in Poland in 2021–2023	2021–2023	(-)
National Programme for Early Detection of Lung Cancer by Low-Dose Computed Tomography	2021–2023	(+/-) discriminatory age criteria
40+ prevention programme	2021–2023	(+)
Ensuring Poland's self-sufficiency in blood and its components for the period 2021–2026	2021–2026	(+/-) 18–65 years age criteria for the donor
Cardiovascular disease prevention programme	2022 to date***	(-!) discriminatory age criteria
Government Health Policy Programme for the antiretroviral treatment of people living with HIV in Poland for the period 2022–2026	2022–2026	(+)
Health policy programme to implement the "Za życiem" comprehensive family support programme for 2022–2026	2022–2026	(-)
Tooth decay prevention programme for adolescents	n.a.–2023	(-)

* provided as part of the guaranteed benefits of health programmes (Rada Ministrów [Council of Ministers] 2018a) (Dz. U. [Journal of Laws] 2018, item 188)
** provided as part of the guaranteed services of a primary care nurse (Rada Ministrów [Council of Ministers] 2019) (Dz. U. [Journal of Laws] 2019, item 736)
*** carried out within the framework of guaranteed services in the field of primary health care (Rada Ministrów [Council of Ministers] 2022) (Dz. U. [Journal of Laws] 2022, item 1355)
(-!) older people were not included, although the health problem addressed by the programme concerned older people
(-) older people were not included as the health problem addressed by the programme did not concern older people
(+/-) older persons included only up to a certain age (e.g., 59, 65 or 74 years)
(+) older persons included in the programme without an upper age limit

Source: own study.

Results

Of the programmes analysed, 12 were aimed at a target group other than the elderly due to the nature of the health problem that was being addressed (prenatal screening, developmental defects, dental care for children and adolescents, treatment of children in a coma, e-addictions in children, postnatal depression, etc.). In the table, these programmes are marked with a (-) symbol.

14 programmes included older people as addressees – in most of these programmes there was no upper age limit or age was not an inclusion criterion (it was

a specific health problem, e.g., HIV, which may potentially also affect older people). Health problems addressed in this group of programmes are not common among older people, so it can be assumed that they have not constituted a very large group of beneficiaries. These programmes are marked in the table with a (+) symbol. On the other hand, descriptions of two programmes clearly state that older people are the target group and the health problems they address are widespread among the elderly – these are the Programme for the Prevention of Depression in Poland 2016–2020 and the POLKARD Programme for the Prevention and Treatment of Cardiovascular Diseases 2017–2021. In the case of depression, the population included people over 65 years of age as a high-risk group, while the POLKARD programme included people over 65 years of age with at least three cardiovascular risk factors.

Another group is made up of programmes with discriminatory age criteria. There were a total of 11 such programmes and they are marked in the table with the (+/-) symbol. Most often, these programmes accept the age of 65 as the upper age limit (e.g., Rheumatoid Arthritis Early Detection Prevention Programme, Colorectal Cancer Prevention), but there are some where this limit is lower, e.g., the Cervical Cancer Prevention Programme targets women aged 25–59.

Among the programmes analysed, there were 3 in which the elderly were not included, although they may have been affected by the health problem addressed by the programme. They are marked in the table with the (-!) symbol. These were:

- Cardiovascular disease prevention programme, which targeted people aged 35, 40, 45, 50 or 55;
- A nationwide programme for the prevention of lymphoedema after breast cancer treatment, which targeted professionally active post-mastectomy women;
- A nationwide programme for the prevention of chronic back pain, which targeted professionally active people.

Health policy programmes are also implemented by the Local Government Units, following their approval by the Agency for Health Technology Assessment and Tariff System. The 2018–2021 report shows that the Agency received 437 final reports on the implementation of these programmes (AHTATS 2021). The largest number of programmes concerned the Mazowieckie Voivodeship (62) and the smallest number concerned the Warmińsko-Mazurskie Voivodeship (6). Among the programmes, the most frequent were those for influenza vaccination among people aged 65 and over, caries prevention, pneumococcal infections prevention and papilloma virus infections prevention. The largest number of programmes that included older people were regional flu vaccination programmes.

In summary, about one-third of the analysed programmes dealt with health problems affecting the elderly and included older people as the addressees. One in three programmes was targeted at other population groups due to the health problem tackled by the programme, while 3 programmes concerned conditions occurring in old age, but were addressed to recipients other than seniors. The last group, which also constitutes one third of the analysed programmes, consists of those whose criteria excluded older people due to exceeding a certain age threshold or being economically inactive, although the problem addressed in the programmes concerns them.

Conclusions and discussion

The analysis of health programmes in the context of the tasks and objectives of health promotion and prevention allows several important conclusions to be drawn. First, the elderly constitute a distinct group of addressees of the analysed health policy and health programmes in Poland. It is reasonable to state that the provisions of health policy with regard to older people are not only formulated at the declarative level, but are also translated into the design and implementation of specific programmes.

Second, the analysis revealed that some of the programmes apply discriminatory criteria (usually age or activity-related), which limit older people's access to the programmes. This is quite a big problem, as it indicates that the state's health policy does not fully take into account the current demographic trend and demographic projections in its planning. In 2008, a review was prepared at the request of the Ombudsman, which revealed similar conclusions – it was found that discriminatory age criteria (e.g., age up to 65 years) were used in prevention programmes and that older people were very often not referred for preventive examinations (Szatur-Jaworska 2008). The problem of ageism in this respect is still present. Informal signals from older people indicate that they feel left out of some health programmes. However, there is a lack of systematic research in this area, thus conclusions could not be drawn regarding the actual evaluation of the offer by those concerned.

Increasing longevity not only means a numerical increase in the number of older people in the general population, but also an increase in health risks, a rise in the number of diseases of old age, increasing dependency, and withdrawal from activity. In the light of the demographic forecasts described above, the inclusion of increasingly older groups of seniors in health and prevention programmes appears to be a justified and necessary measure. Good examples of this include inclusion in prevention programmes concerning colorectal cancer, malignant tumours of the urinary tract, and female genital malignancies, which are the most common causes of death in the elderly, and the number of deaths increases with age. In light of the statistical data, if health programmes were to be set up to address these specific problems, they should include all older people, without limiting accessibility to, for example, only those under 65 or 70 years of age.

Third, the above analysis shows a gap between the health problems targeted by the programmes and those actually found in the elderly population. While cardiovascular diseases are reflected in the programmes, some of them use discriminatory criteria. Osteoarticular diseases, diabetes mellitus, ischaemic heart disease, chronic digestive diseases, peripheral nervous system diseases and thyroid diseases are the health problems most frequently reported by seniors to the PCP. These are not reflected in the programmes, similar to the case with the aforementioned types of cancer that represent the second most common cause of death among people aged 60+.

Fourth, there is an apparent lack of health promotion and primary prevention programmes targeted at older people. Promoting individual responsibility for health, strengthening health resources and encouraging health-seeking attitudes among older people are not translated into specific national programmes as objectives formulated in health policy. This can lead to inappropriate attitudes among older people towards their own health, characterised by low awareness of health-enhancing activities and passivity in terms of health responsibility, which is contrary to the idea of active, healthy and successful ageing at the heart of the national health policy. Issues concerning the importance of taking informed action directed at strengthening one's own health potential and avoiding risk factors among older people are widely reported in the literature. A distinction is made between physical health-related behaviours, psychosocial health-related behaviours, preventive behaviours and avoidance of anti-health behaviours. (Muszalik et al. 2013). Health-promoting behaviours enhance individual and population health, with the goal of successful ageing and active old age (Zamorska and Makuch 2018). Health status among older people is also influenced by factors such as physical activity, proper nutrition, prevention and the living environment. Another important factor is the individual's resources to effectively cope with stress.

Health-promoting practices among the elderly in Poland are determined by educational level, family situation (being in a relationship) and participation in Universities of the Third Age. Particularly the latter factor seems to be important from the point of view of preventive measures (Muszalik et al. 2013). Physical activity is age-determined – in light of data from the *PolSenior 2* survey, the level of activity indicated by respondents was stable until the age of 70–74, after which it decreased significantly. The most common activities performed by the older people were walking and working in a garden. The research cited above also shows that the physical activity of older people is determined by their level of education, while some forms of activity are determined by the size of their place of residence. Most often, older people indicated that they participated in these activities for health, for pleasure, and out of a need to relax (Kostka et al. 2021). The diets of older people depend on their financial situation, education, place of residence and age. The greatest dietary disturbances are present among the oldest seniors, residents of small towns and cities, and among those with low material status (Wernio et al. 2021). Health behaviours also depend on social support and psychological factors such as sense of coherence, personality, life optimism, mental resilience, sense of control, and spirituality (Zadworna 2012; Zadworna-Cieślak and Ogińska-Bulik 2012; Mędrela-Kuder and Bogacka 2017; Rembecka, Sztuba and Łakomska 2020). It seems reasonable to strengthen the health of older people by implementing health promotion campaigns.

Summary

The article achieves two stated objectives. It presented the tasks of health policy in the field of prevention and health promotion in relation to the elderly, both from a scientific perspective and on the basis of existing strategic documents. It also analysed nationwide health programmes in order to verify how the implementation of health programmes functions in practice in the light of the tasks and goals assumed in the health policy of the ageing society. The analysis made it possible to verify the hypothesis concerning too little consideration of the elderly as addressees of these programmes. The results indicate that:

- older people are a distinct group of addressees of the analysed health policy and health programmes in Poland;
- some programmes apply discriminatory criteria that prevent older people from accessing the programmes;
- there is a mismatch between the health problems targeted by the programmes and those actually utilised by the older population;
- there is a lack of health promotion and primary prevention programmes targeting older people.

The above conclusions allow for a cautious confirmation of the hypothesis posed at the beginning of the article, stating that nationwide health programmes take too little account of older people as addressees. Although many programmes are addressed to older people, some of them use discriminatory criteria, mainly age-related. As the population ages, morbidity rates change and the age at which certain conditions are acquired is delayed, but health programmes do not take these changes into account, excluding people who have reached a certain age. Additionally, the health issues addressed by the programmes only partially address the health problems of old age.

The final recommendations derived from the article for the purpose of scientific theory and practical health policy actions can be outlined as follows:

- it is necessary to design research studies aimed at analysing older people's experiences of utilising the health programmes on offer. Such research should include not only the evaluation of programmes in terms of inclusion/exclusion criteria, but also address perceptions of programmes offered in general, awareness of the role of prevention and health promotion among older people, and individual practices undertaken by seniors to strengthen health;
- it is necessary to revise the inclusive age criteria in existing programmes and to design further programmes taking into account the longevity perspective and the changes in the incidence of certain diseases among seniors whose longevity is increasing;
- it is recommended that programmes be designed to take greater account of the relevant health problems of the elderly;
- it is essential to take action to raise awareness of the importance of health-oriented activities rather than disease management, and to promote active, informed choices and lifestyles among older people that will foster the strengthening and maintenance of health.

The right to health is guaranteed to everyone, but securing it in old age requires comprehensive measures combining scientific knowledge of the ageing process with government and local authority decisions stemming from the specific policies adopted and from an active attitude towards one's own health among those concerned.

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The Idea of Occupational Justice and Difficulties with Its Implementation in Polish Conditions on the Example of People with Mental Disorders

Occupation is one of the basic human needs. The term refers to all activities that people need to, want to, and are expected to do. It includes activities of daily life related to self-care, productivity and leisure time, named, defined and having a value given to them by individuals and culture. Human beings are occupational beings, and occupation is an active element of human existence, necessary for health as it is understood in the broadest sense.

The right to pursue activities relevant to the individual, which is enshrined in the concept of occupational justice, is often not reflected by the opportunities available to individuals or groups facing various types of limitations, e.g., disabilities, mental disorders, social exclusion, etc. Limited awareness, unavailability of support, funding difficulties – this is the grim reality both for people struggling with certain difficulties and for those who look after their care.

In this article, the idea of occupational justice is contextualised within the Polish reality of health care and social care directed to people with mental disorders.

Keywords: occupation, occupational justice, occupational injustice, mental health.

Introduction

According to the idea of occupational therapy, every human being is an occupational being, regardless of his or her age, gender, race, health or level of fitness. Occupation is inscribed in a person's life, from birth to death (Reilly 1963). The opportunity to pursue occupation should be the right of every individual,

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regardless of their health, gender, age or other characteristics. Unfortunately, this ideal is not achieved in practice, especially for people who struggle with various types of limitations, including mental disorders.

The aim of this article is to present the idea of occupational justice and to analyse the situation of people with mental disorders in Poland in terms of equal access to occupation, based on available source materials.

In order to meet the objectives of the article, it is necessary to outline the scope of the meaning of the terms "occupation" and "occupational justice".

According to the World Federation of Occupational Therapists (WFOT 2012), occupation refers to all the things people need to, want to, and are expected to do. Occupation is therefore something that occupies people's time and attention. The term is used to describe activities of daily life that are named, organised, and have a specific value given to them by individuals and culture. They include everything that people do in terms of self-care and the enjoyment of life, as well as all the things that contribute to strengthening their communities socially and economically (Law et al. 1997: 32). Occupation is therefore a guided activity, taking into account the needs, abilities and preferences of the person doing it. In occupational therapy a distinction is made between self-care activities, e.g., washing, dressing, preparing meals, eating, and mobility, and leisure activities, e.g., playing sports, establishing and maintaining social relationships, pursuing hobbies; and productivity activities, e.g., working, studying.

Occupation is an active element of human activity that is necessary for broadly understood health and well-being. Occupational activity depends on the health of the individual. On the other hand, activity significantly affects health. According to the definition promoted by the World Health Organization (WHO), health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity. This view of health takes into account not only its biological dimension, related to the functioning of the body, but also its mental dimension, relating to the functioning of the mind and emotions, and its social dimension, reflected in social participation. Health is therefore multidimensional, with its components influencing each other. It can be assumed that in a healthy person the components of health, i.e., physical, mental and social functioning, are in a state of balance and integration. Health is treated as a process of maintaining a dynamic balance between the demands of the environment (internal and external) and the potentials possessed by an individual (Juczynski 2016: 21). Nurturing health requires both effort and the appropriate skills to maintain the balance in the face of changes that are constantly taking place, both in the individual's environment and in his or her body. One of the factors directly related to health is precisely the individual's occupation. Performing an occupation has physical, mental, and social dimensions. For example, preparing a meal requires the use of physical resources – the ability to move, a functioning upper limb (or equipment adapted in a way that a person with limitations could make use of it), etc. The psychological aspect plays here an important role – a sense of empowerment, satisfaction, etc. Equally important is the social dimension – the meal may be for relatives or it may be a work-related task. Occupation should be accessible to everyone, regardless of their individual characteristics, social standing or cultural background.

In occupational therapy, the idea of occupational justice, according to which every person should have the right and opportunity to engage in occupations that are important to them, is widely emphasised. The promotion or limitation of occupational justice (the right and opportunity to engage in an occupation), is linked to a number of structural and contextual factors. Structural factors include occupation-related determinants, such as: type of economy, regional/national/international policies) and occupational instruments or programmes (i.e., health and social support, education, employment). Contextual factors relate to age, gender, religion, sexual orientation, health status, disability, etc. The relationship between structural and contextual factors is reflected in conditions that either favour or limit occupational justice, the latter resulting in occupational injustice. However, the essence of occupational justice is precisely the individual's right to pursue an occupation, taking into account its meaning, the possibility of participating in it, the possibility of choosing the occupation and of maintaining the occupational balance (Townsend 2012).

According to the World Federation of Occupational Therapists (WFOT 2006), every person has the right to have their participation in occupations supported, to be a full member of their family and community. Everyone has the right to participate in occupations that enable them to develop, that give them fulfilment and satisfaction and that are compatible with their beliefs and culture. The right to occupation takes into account civic, educational, creative, and spiritual activities and is based on the recognition that each person's contribution is of value to the whole community. Important threats to occupational justice include economic factors (poverty), illness, social discrimination, natural disasters, and armed conflict. Additionally, opinions about occupational justice are linked to religious beliefs, culture and as well as to environmental and institutional conditions (Misiorek 2019).

Adopting an occupational justice perspective allows for a deeper analysis of the situation of individuals and groups precisely in the context of this phenomenon. As already mentioned in order to better illustrate the issues at hand, this article chooses to describe the situation of people with mental disorders.

People with mental disorders in Poland

An attempt to describe the situation of people with mental disorders should start with a characterisation of this population. Unfortunately, the difficulty arises already when searching for definitions in legal documents. In the Polish Mental Health Protection Act currently in force (Rada Ministrów [Council of Ministers] 1994), there is no definition of "mental disorder" or "mentally ill person", despite the fact that these terms occur repeatedly in the text of the Act. Instead, it is stated that:

> Whenever the provisions of this Act provide for a person with a mental disorder, this refers to a person who: is mentally ill (exhibiting a psychotic disorder), has an intellectual disability, exhibits other disturbances of mental functions which, according to the state of medical knowledge, are classified as mental disorders, and the person requires health services or other forms of assistance and care necessary for living in a family and social environment (Rada Ministrów [Council of Ministers] 1994).

This description is very general and therefore open to various interpretations, which should not be the case.

In the *International Statistical Classification of Diseases* and *Related Health Problems* ICD-10, developed by the World Health Organization (WHO), currently in force in Poland[2], mental disorders are described in the chapter entitled *Classification of Mental and Behavioural Disorders*. They are divided into 14 diagnostic categories, examples of which include: affective disorders, neurotic disorders, disorders of psychological development, personality disorders, intellectual disabilities, etc.

Carried out between November 2010 and March 2011, the first epidemiological study of mental disorders in Poland was conducted on a random sample of more than 10,000 respondents aged 18–64 in accordance with the methodology of the World Health Organization (WHO) and in collaboration with the World Mental Health (WMH) Consortium, in which the Composite International Diagnostic Questionnaire (CIDI) was used. It was carried out as part of the "Epidemiology of Psychiatric Disorders and Availability of Psychiatric Health Care. EZOP – Poland" Project (Kiejna et al. 2015). The study report indicated that in the population studied, at least one disorder out of 18 defined in the classifications (ICD-10 and DSM-IV) could be diagnosed in 23.4% of people – Polish residents of working age – during their lifetime. The most common were substance abuse disorders (12.8%), including alcohol abuse and dependence (11.9%), and drug abuse and dependence (1.4%).

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[2] On 1 January 2022, a revised version of the ICD classification numbered 11 was adopted. However, until it is officially translated, the provisions contained in the ICD-10 version remain in force. Poland, like other countries, was given a 5-year period to implement it and adapt it to the national system.

The next most prevalent group of disorders were neurotic disorders, among which specific phobias (4.3%) and social phobias (1.8%) were the most common. Overall, all forms of neurotic disorders affected approximately 10% of the study population (2.5 million Poles). Mood disorders – depression, dysthymia or mania – were jointly diagnosed in 3.5% of respondents (approximately 1 million Poles). Impulse-control disorders: oppositional defiant disorder, behavioural disorder, intermittent explosive disorder, attention deficit hyperactivity disorder (ADHD), were diagnosed in 3.5% of respondents (approximately 1 million Poles).

Another EZOP II study, entitled “Comprehensive Study on the State of Mental Health of the Population and Its Determinants” was carried out in 2018–2019 on a representative sample of 15,000 people. In the 2nd edition of the study children were also included in the sample, divided into age groups 0–6 years and 7–17 years (Moskalewicz, Wciórka 2021). The report indicates that disorders of psychological development affect as many as 400,000 of the youngest children, and more than 500,000 children in the age group 7–17 years have a history of mental health disorders. More than 8 million adults in Poland (1/4 of the population) experience various mental disorders. More often people affected by mental disorders are poorly educated, lonely, and those who have dropped out of the labour market.

It is worth noting that the EZOP II study was carried out before the COVID-19 pandemic. The pandemic and the associated sense of threat to one’s own and loved ones’ health and lives, feelings of insecurity, and other associated emotions may contribute to increased psychological distress, including depressive symptoms and anxiety in the general population affected by the pandemic, as confirmed by a number of findings from studies carried out in various countries (e.g., Jia et al. 2020; Mazza et al. 2020). Hence, it is speculated that if the EZOP study was repeated in the current year, the results could further highlight the magnitude of the problem.

Situation of people with mental disorders – an attempt at description from an occupational perspective

Mental health problems are related to other aspects of an individual’s functioning: cognitive, motor, individual or social. In practice, this results in, for example, limitations in one’s ability to perform work or daily activities, a reduction in the quality of one’s work or having to put more effort into it. The consequences of mental disorders are experienced as troublesome, fostering unfair treatment or considered as a source of significant disruption in relationships with family and friends (after Niemczyk-Zając 2021).

An analysis of the situation of people with mental disorders from an occupational perspective may be facilitated by referring to one of the models used in occupational therapy, the PEO model (Law 1996). The Person-Environment-Occupation (PEO) model emphasises occupational performance as shaped by the interaction between person, environment and occupation. Occupational performance can be measured objectively, but the individual's satisfaction with the task is also important. The person domain includes role, self-esteem, cultural background, personality, health, cognitive function, physical fitness and sensory abilities. The environmental domain includes the physical, cultural, institutional, social and socio-economic environment. Occupation, on the other hand, refers to the tasks that a person performs and through which they are able to support themselves, that allow them to express themselves and obtain fulfilment. These three domains are interdependent and mutually influence each other. This model can facilitate the understanding and analysis of problem domains that have their consequences precisely in the domain of occupational performance, which is a complex and dynamic phenomenon that changes in different periods of life and environmental circumstances.

Using the PEO model, an attempt can be made to describe the situation of people with mental disorders. Referring to the first domain of the model – the person – it is worth emphasising the fact that each individual is unique. The person is seen holistically as consisting of body, mind and spirit, and is characterised by many elements including self-concept, personality type, personal competences and cultural background. In the case of people with mental disorders, it is possible for them to experience various limitations, e.g., motor, cognitive or related to the area of social participation. This uniqueness also relates to the fact of experiencing the illness, its dominant symptoms, the level of acceptance or lack of acceptance, the motivation for treatment. There are no two identical individuals with schizophrenia or suffering from affective disorders, nor are there identical children with disabilities. Apart from individual factors, people are differentiated by their environmental context, family situation, and availability of support. These factors have their repercussions in the self-image inherent to the individual. Available research indicates that people with mental disorders are characterised by low self-esteem, unawareness of their own rights, low levels of education, reduced productivity, and poor social relationships (Kaszyński 2013). In these individuals, the occurrence of anxiety related to the disclosure of the illness (the so-called Goffmanian internalised stigma [Goffman 2007]) and reduced motivation to act have also been noted. The postponement of benefiting from available help or rejecting it, which can also be observed in this group of people, may be related to stereotypes related to mental disorders. The rigidity of social attitudes and related behaviours, characterised by distance and exclusion of the mentally ill, effectively discourage people with difficulties from talking about them and seeking support (according to the results of the EZOP II study). Equally complicated are the possibilities for people with mental disorders to perform social roles. Difficulties are already apparent at the lowest levels of education. Article 1 of the Act on the Education System indicates that the school is obliged "to adapt the content, methods and organisation of teaching to the mental and physical abilities of students, as well as to provide the possibility of using psychological and pedagogical assistance and special forms of didactic work" (Rada Ministrów [Council of Ministers] 1991). Unfortunately, the implementation of this provision in practice leaves much to be desired. For example, the NIK (Supreme Audit Office) audit showed that in the 2020/2021 school year in some schools psychological and pedagogical assistance classes were either organised in an inappropriate manner or were not provided to all students who had such indications in the opinions or judgments of psychological and pedagogical counselling centres. It was also emphasised that groups which took part in didactic-compensatory and corrective-compensatory classes were too large, which made it difficult for teachers to achieve the set goals. NIK also expressed reservations about the working conditions in schools concerning, among other things, the poor equipment in the institutions and persistent overtime of teachers (NIK 2021). It is also worth emphasising that factors related to a given mental disorder can often result in a child requiring hospitalisation or staying at home, which has an impact on the child's limited fulfilment of his or her role as a pupil, colleague or class member. For adults, difficulties are related to the fulfilment of the role of a worker, which in occupational therapy is included in the area of occupational productivity. Observation of the situation of people with mental disorders in the labour market allows us to notice the insufficient protection of the rights of employees with mental disorders, the lack of economic and stimulating mechanisms for employing this category of people, the high level of unemployment in the local labour markets, as well as the lack or low level of knowledge among employers about the financial benefits associated with employing people with mental disorders (Kaszyński 2013).

The second domain refers to the environment, which is considered very broadly and includes cultural, physical and socio-economic contexts. The environment therefore does not only mean the physical, residential conditions; the cultural background also refers to the immediate people, the local community and the wider society. The potential of the environment for change seems unlimited. Realism, however, dictates a modification of this belief – while making adaptations in the physical environment, e.g., adapting accommodation to a person's needs, is usually feasible, changing attitudes towards people with mental disorders is extremely difficult. According to the results of the EZOP II report, rigid and reluctant stereotypes can still characterise attitudes towards mentally ill people, mental disorders, and psychiatric care institutions. More than half of the Polish population does not accept the ill in their environment, and is also reluctant to see the establishment of mental health-related institutions in their place of residence (Moskalewicz, Wciórka 2021). The organisation of psychiatric care and the availability of mental health professionals can be described as insufficient.

Vocational rehabilitation is not integrated with clinical services, vocational activation programmes are characterised by low effectiveness, and there is a lack of work experience and internship spots for people with mental disorders (Kaszyński 2013).

The third domain of the model is occupation. It is considered essential to the person's internal needs with regards to self-care, productivity, and leisure time. Performing an occupation gives the individual a sense of being competent, self-reliant, and being able to do what is meaningful and needed. It is noteworthy that occupation is also related to the social roles performed by the individual – is stems from the role and also allows the individual to fulfil it. The need for occupation occurs at every stage of life regardless of a person's level of fitness or state of health. It is worth noting that in some situations, the physical "execution" of certain occupations may prove significantly challenging. Townend and Polatajko (2007) emphasise that in order to capture the broadest perspective of human occupation, occupational engagement should also be taken into account. For example, when observing people who are bedridden, it is difficult to observe the performance of an occupation in a strict sense, but what is important is what the person experiences and feels in relation to the occupation. Engagement can mean making choices, expressing one's will and exercising control over certain aspects of one's life (Misiorek 2019). A person who is bedridden, for example, is physically unable to perform an activity such as dressing, but may nevertheless be involved in it, e.g., by making choices about clothing, its colour, etc.

The above-mentioned components of the PEO model are dynamic and mutually influence each other. Understanding the essence of the different components and their relevance with regard to occupation is crucial for making effective interventions aimed at supporting people struggling with mental disorders.

The concept of occupational justice in the Polish context

In Poland, psychiatric health care comprises three basic organisational forms. The first of them is outpatient care, with its primary component being mental health clinics where active care is provided. Inpatient care includes hospitalisation. Indirect forms, on the other hand, involve treating a person without separating them from their environment and include day wards, community treatment facilities and hostels. Forms of social support are also available, such as specialised care services for people with mental disorders, community self-help homes and social care homes. Tasks related to vocational rehabilitation are carried out in occupational therapy workshops, and tasks related to socio-occupational rehabilitation are performed in vocational activity centres, among others (Niemczyk-Zając 2021).

The facilities mentioned above are just an example serving to illustrate that, in theory, help for people with mental disorders is available. In reality, however, in certain situations both the health and social care systems are inefficient (Niemczyk-Zając 2021).

How is the idea of occupational justice implemented in Polish conditions? Do people with mental disorders have the right and the opportunity to be involved in occupations that are important to them?

The answers to the above questions are not unequivocal. On the one hand, every individual has constitutional rights, while on the other hand, the possibilities of exercising these rights are quite debatable. Examples of limitations concern the possibility of supporting the health of individuals whose condition either enables or limits the ability to perform an occupation. These limitations include, among other things, access to specialist physicians. According to data as of 30 April 2022 made available by the Supreme Medical Chamber in Warsaw, in Poland there are currently 5228 psychiatrists (including 531 child and adolescent psychiatrists), of which 4926 are practising specialists.

Polish law does not sufficiently protect people with mental disorders against exclusion, in particular against discrimination on the labour market, and does not ensure access to education and the above-mentioned health services to an adequate extent (Moskalewicz, Wciórka 2021). Referring to the terminology specific to occupational therapy, one can consider limitations regarding occupations within the domain of productivity, which encompasses professional work and education.

The already-cited results of the EZOP II study highlight the disproportionate prevalence of social development disorders among children under 6 years of age living in urban versus rural areas (in rural areas the prevalence rate is twice as high), as well as the disproportionately high prevalence of disorders among children aged 7–17 in families receiving social care (Moskalewicz, Wciórka 2021). This situation should lead to decisive action directed at the provision of support and treatment, as well as the development of community health care directed at cooperation with the family and educational institutions, among others.

The vast majority of people with mental disorders do not receive or benefit from adequate assistance, which does not go hand in hand with the idea of occupational justice. The individual's right to exercise occupation is often already limited at the level of awareness by stereotypes. Most often, these stereotypes propagate ideas that people with disabilities pose a danger to those around them, are irresponsible and unpredictable, and are intellectually less able. These beliefs result in infantilising people with mental disorders, ignoring their rights and treating them with pity (Lejzerowicz, Książkiewicz 2012).

It is worth emphasising here the potential of occupational therapy, which in Poland remains untapped. The profession of occupational therapist is included in the group of medical professions, and persons holding a bachelor's degree have the necessary knowledge and skills to undertake effective activities directed precisely at the area of human occupation. Reports in the Polish language regarding activities that occupational therapists, educated to the best world standards, can undertake are quite limited in number. There are, however, many foreign-language publications on the subject (Castro et al. 2016; Hammond 2004; Algeo, Aitken 2019). According to a review of the available global literature, the most common of the interventions used by occupational therapists is psychosocial intervention aimed at reducing the symptoms of the disorder, occupational recovery and social and occupational reintegration of people with mental disorders. Subsequently, psycho-educational interventions are applied which aim at acquiring disorder management skills, increasing social skills such as non-verbal communication, and enabling the patient to perform meaningful activities such as reading. Equally frequently implemented interventions include cognitive interventions aimed at improving cognitive function, exercise interventions directed at compensating for the cognitive impairments common in psychiatric disorders, increasing participants' knowledge and understanding of rules, and enhancing their teamwork skills (Rocamora-Montenegro 2021; Wilburn et al. 2021).

The presented considerations indicate a number of weaknesses related to the implementation of the idea of occupational justice for people with mental disorders in Polish conditions. The resulting effect, however, should not be stagnation, but the revision of actions taken and the generation of new effective solutions, so that everyone, including those struggling with illness as well as healthy people, can realise what is important to them, what they need and what gives their life meaning.

Summary

How can the idea of occupational justice be strengthened in Poland? It is worth thinking about some of the following postulates.

First justice requires social responsibility for enabling all members of society to perform occupations that are important to them (Townsend 2012). Responsibility is required at both the societal and institutional level, but also at the individual level by accepting that mental disorders are egalitarian and that those affected are and should be treated as full participants in society. This requires working towards replacing stereotypes, which is a difficult and long-term process. Although the durability of stereotypes and the failure (to date) to renounce them has been pointed out by researchers. Nevertheless researchers likewise seek ways to weaken the stereotypes as described, for example, in models of stereotype change theory of so-called "out groups" that take into account the potential for empathy (Finlay, Stephan 2000; Batson, Polycarpou 1997).

Second, changes are needed at the institutional level related to housing, employment, recreation and others, which means supporting the subjects and institutions that operate in these areas, both by educating their representatives about the resources available to people with mental disorders and by providing the means to take decisive supportive measures, e.g., developing sheltered housing, supporting entities focused on providing employment to people with mental disorders or implementing social projects aimed at their inclusion.

Third, the development of occupational justice for people with mental disorders requires the development of targeted programmes and the creation of conditions for the real involvement of these people in occupations as well as the promotion of their social participation.

Undertaking the above-mentioned actions requires an adequate background, both in the form of appropriate legal regulations and financial resources, as well as the use of sound scientific knowledge, openness towards the other person, and behavioural changes. Humanity and mutual respect should be the basis of social relationships, no matter who the participants in that relationship are or what they are up against.

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Selected Aspects of "Alternative" Ways of Meeting the Sexual Needs of People with Disabilities: Sex Worker – Sexual Assistant – Surrogate Sexual Partner

Most researchers focus on sex workers when analysing the phenomenon of prostitution. A definite minority includes studies on service recipients. Few publications refer to the fulfillment of sexual needs of people with disabilities.

In the presented article, the author takes a closer look at selected aspects of the phenomenon involving the fulfillment of intimate/sexual needs of people with disabilities by sex workers, sex assistants, surrogate sex partners, citing selected research results from found materials.

The author outlines the functioning of the phenomenon in relation to legal, ethical, social, and medical issues, using the example of selected solutions applied in several countries to refer to the situation in Poland.

Keywords: disability, sexual needs of the disabled, sex working, prostitution, sex worker, sexual assistant, surrogate sexual partner, sexual assistance, sexual care

Introduction

In most cultures, a normative approach to sex prevails. Kochanowski (2013) points out that, as part of a certain kind of script, sexual behaviour is segregated into: acceptable – considered healthy and acceptable in a given social space – moral, and immoral. The roots from which a given culture originates play an important role. Thus, within the Judeo-Christian heritage, to which Poland belongs, sex is subjected to moral evaluation in relation to its function. The most desirable function is the procreative one, performed within the framework of a permanent,

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monogamous marriage between persons of the opposite sex. Love constitutes another value, with pleasure being forced to give way to the other functions. The compulsory sexual scenario thus established brings with it profits in the form of respect shown to the main actors and recognition as moral citizens, the support of the state offering resources limited or unavailable to citizens honouring values other than the "supreme" procreative value of sex. Sexual behaviour that deviates from this moral centre is exposed to harsh judgement, which intensifies as one moves away from the designated "ideal". Within different cultures, the typical "sexual margin" includes people who decide, for example, to have "casual sex", not realised within a relationship. Kochanowski points out that people who admit to this type of sexual relationship clash with condemnation and denial of the individual's morality, and calls this phenomenon an anti-sexual paranoia. Within this social attitude, immoral sex creates a threat to the individual as well as to society. It is the source of a system of sexual segregation. Representatives of the sexual margin, for their own safety, should take care to conceal the needs they feel and the behaviour they undertake in order to avoid stigmatisation. "Anti-sexual paranoia is not just the beliefs or attitudes of individuals towards those who engage in sex that does not conform to cultural scripts of normative correctness. It is an institutionalised, embedded system of discrimination, humiliation, marginalisation, discrediting, but also the use of various forms of violence (including physical violence) against the sexually insubordinate" (Kochanowski 2013: 19). Prostitution as well as particular "alternative" ways of meeting the needs of people with disabilities are phenomena that often go beyond the framework of the indicated propriety.

Sex workers[2] at the turn of the twentieth century were attributed excessive sensuality (e.g., H. Ellis, W. Morosso), sexual frigidity (e.g., C. Lombroso, M. Hirschfeld, F. Merrick), and sexual indolence (e.g., D. Hammer) in their assessment of sexual desire, with scholars now refuting these beliefs stigmatising prostitutes (Sosnowska 2019: 27). In contrast, people with disabilities[3] are often viewed through the prism of myths about their sexuality – they are attributed asexuality or hypersexuality, and attempts to express their sexuality are often met with resistance from those around them (Hilberink 2022: 820). As Obuchowski notes, the sexual-erotic act under certain conditions acquires social significance: many women only feel self-confidence when they are desired, men with certain defects or low social status gain a sense of importance and value through sexual

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[2] I use the terms "prostitution", "sex work", "paid sex", "sexual services" and respectively, "prostitute" and "sex worker" interchangeably, neutrally and without stigmatising individuals, which is raised by some researchers when using the terms "prostitution" and "prostitute".

[3] I use the terms "disabled", "person with a disability" interchangeably, neutrally and without stigmatising individuals, which is raised by some researchers when using the term "disabled".

prowess (Obuchowski 1974: 146). It seems that the perception of sexuality of people engaging in prostitution as well as the disabled is a good example of the attitude towards this social group as such and the rights they should, or should not, have as part of civil society.

The fulfilment of the sexual needs of people with disabilities has been a taboo subject, and many stereotypes have grown around this issue (Lew-Starowicz 1999). As Trojanowska notes, "the perception of people with disabilities as incapable of leading an active and satisfying sexual life has no cultural or ethnic boundaries" (2020: 62). Slowly, the situation of the perception of sexuality of disabled people is changing, both within social and scientific discourse and on the ground of law. The Convention on the Rights of Persons with Disabilities, adopted by the United Nations General Assembly on 13 December 2006, was ratified by Poland on 6 September 2012. It contains, among others, provisions prohibiting discrimination against persons with disabilities as well as mandating the creation of conditions that enable the exercise of rights on an equal basis with others, and constructing solutions dedicated to persons with disabilities.

People with disabilities are less likely than non-disabled people to report leading a satisfying intimate life. Accommodation limitations, lack of privacy, and insufficient sex education are some of the most common barriers they face (Hilberink 2022: 820). The awareness and knowledge of the sexuality of people with disabilities and the declarative acceptance of the fulfilment of the sexual needs of society intersect with the difficulties that disabled people still face both when trying to use "standard" (culturally perpetuated) and "alternative" ways to fulfil their desires (Ślęzak 2016a: 60). "Alternative" ways of sexual fulfilment include sexual services provided by prostitutes, sexual assistants and surrogate sexual partners[4].

Given the different models of normative regulation of prostitution around the world, it is worth noting their impact on the realisation of "alternative" ways to meet the sexual needs of people with disabilities. The two phenomena are correlated to the extent that prostitution itself is not a rigidly defined phenomenon that is locked into a fixed framework with regard to its manifestations, types, and boundaries of what falls within and what goes beyond the provision of sexual services. Also, an in-depth analysis of the phenomenon allows conclusions to be drawn as to the diversity of models of normative regulation of prostitution and the social acceptance of the phenomenon often independent of legislated law (Sosnowska 2019). Similarly, with "alternative" ways of satisfying the disabled, we have to deal with the lack of a rigid nomenclature, the interchangeable use

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[4] On the area of sexual rehabilitation, deliberately omitted in this article, write, among others, Auoil (2010), Adamczyk et al. (2012), Ślęzak (2016b).

of terms for the same or different phenomena, as well as a phenomenon that arouses controversy in itself.

It is noteworthy that both phenomena, the provision of sexual services – including "alternative" ways of fulfilling the sexual needs of people with disabilities – and the sexuality of people with disabilities, belong to a taboo zone. Due to the limited research in this field, it is difficult to come to general conclusions about "alternative" forms of satisfying the desires of people with disabilities. The analysis of foundational data can only provide a general perspective on the issue by relating it to a variety of research findings from several countries. The aim of this article is to highlight the problems arising from the fluidity of the terms and of the scope of "alternative" sexual services provided to people with disabilities, to outline how they are implemented and the legal challenges faced by service providers as well as service recipients, to cite examples of research findings from the still scarce literature in this area, to signal the convergence of both phenomena and challenges, including the issue of stigma faced by service providers or people with intellectual disabilities, where the realisation of the right to the fulfilment of sexual desires is not as obvious as it might seem.

In view of the above, it is worth analysing selected aspects, starting with an overview of disability models and the topic of the sexual needs of people with disabilities, then moving on to introduce sex workers, sexual assistants and surrogate sexual partners as representatives of service providers in the field of "alternative" ways of fulfilling the intimate needs of persons with disabilities, and presenting an overview of the problems encountered in the realisation of their services, identified on the basis of the cited research results, introducing in turn the legal and ethical aspects and some arguments used in the debate "for" and "against" the described sexual services for persons with disabilities, ending with an outline of the situation of the phenomenon in Poland.

Models of disability

There are currently mainly two models of disability. In the medical model, where the focus is placed on the effects of illness or injury, people with disabilities are offered medical services to combat deficits and impairments perceived as a problem, a disorder, a taboo phenomenon (Ciechomska et al. 2021: 123). In the social model, disability is considered as a social construct and barriers are imposed on functionally diverse people in a given context, so it is important to eliminate architectural impediments and attitudes that hinder the equal opportunities that every citizen should be provided with (Gutiérrez-Bermejo et al. 2022: 348). The social model is linked to the biopsychosocial model, which is currently gaining importance, in which disability is seen as a process in dimensions that go beyond the biological or social spheres and include psychological, cultural, social, and political perspectives, among others (Ciechomska et al. 2021: 123).

There is noticeably less acceptance of people with intellectual disabilities than physical disabilities (Giryński et al. 1993; Kijak 2007). Kijak points out that while entering into a collegial and friendly relationship with a person with a disability is considered by the majority of non-disabled respondents (N=130), emotional relationships are considered by only 4% of men and 3% of women (Kijak, 2007: 19). The researcher also believes that although she observes a shift from biologism to a sexual rehabilitation approach for people with intellectual disabilities, despite seeing evidence of the granting of "specific sexual rights and freedoms to people with disabilities (…), there is still an infantilisation of adulthood for people with disabilities" (Kijak 2011: 150). At the root of the denial of the right to express sexuality and establishing sexual relations for people with intellectual disabilities, Kijak notes the perception that they are either "perpetual children" with no educational needs, or dangerous persons due to the recognition that they are unable to control their own urges. She judges the denial of the existence of the sexuality of people with intellectual disabilities as immoral and equates this action to taking away part of a person's personality (Kijak 2011).

Many researchers and specialists speak in favour of sexual education and the right to make one's own decisions by persons with disabilities, pointing to the right to freedom and equality (e.g., Izdebski, Długołęcka, Fornalik, Kijak, Lew-Starowicz). On the other hand, the conviction of the inheritance of disability raised by other researchers provides a basis for non-acceptance of the realisation of sexual life and procreation by people with intellectual disabilities (Pilecka 2004; Ślęzak 2016a: 61)[5].

Izdebski's (2005) research shows that in a survey group of 1004 people over 15 years of age, acceptance of sexual fulfilment for people with physical disabilities is expressed by 69% of people (full acceptance 74%) and for people with intellectual disabilities by 54% (full acceptance 39% of respondents), (Ślęzak 2016b: 60). McConkey and Leavy's (2013) 2011 survey of 1,000 Irish respondents indicated that 69% of respondents acknowledged the equal right to sexual fulfilment for people with physical disabilities (50% in 2001), and only 45% for people with intellectual disabilities (Gilard et al. 2019: 111).

Kijak notes that "methods of psychosexual support for people with intellectual disabilities have been developed in many countries. Numerous counselling and sex therapy programmes, used in Western European countries and some states of the United States of America, often abound with modern solutions and ideas. In Poland, there are still few such examples" (Kijak 2011: 149).

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[5] More on the approach to the sexual sphere in people with profound intellectual disabilities, including the division into desexual-avoidant orientation, sexual-totally-acceptant orientation, and sexual-subliminal orientation is written by Nowak-Lipinska (1996).

Sex worker

There is no single definition of sex work, and it is noteworthy that an accurate understanding of the phenomenon plays a significant role in the creation and establishment of normative acts and the consideration of new forms as well as the implementation of public policies in this area. Błońska (2010) draws attention to the relationship between the way prostitution is defined and the scientific discipline. Syrek (1979) points to three levels of consideration of the definition of the phenomenon: historical relativism, geographical relativism, and the structural plane (Ślęzak 2016a: 53). As a researcher, "I consider prostitution to be the provision of sexual services, in exchange for material or non-material benefits received, without any link to a specific form of remuneration, with a lack of emotional connection between service provider and recipient, and with associated issue of the number of clients or the type of services provided" (Sosnowska 2021: 110). In the case of sex workers, we may be dealing with people who choose to receive additional training to assist people with disabilities, or their services are performed as "standard" and as for any other client. Ślęzak notes that prostituting female respondents in Poland express aversion to services provided to people with disabilities, by pointing out the greater commitment required with a client less able than others (Ślęzak 2016b). In addition, people with disabilities are warned against using prostitution services because of, among other things, the risk of theft (Kaufman et al. 2013). WHO/UNFPA (2009: 6) point out that people with disabilities are three times more likely than non-disabled people to be victims of psychological violence, physical violence and rape, and that intellectual disability predisposes to an even higher rate of risk, and while these are general findings and do not refer directly to relationships with sex workers, they highlight an issue that is also relevant in relation to paid sexual services offered by sex workers.

Liddiard's research into the motivations of 16 male respondents with disabilities using the services offered by female sex workers found that, unlike non-disabled men, they were not primarily rooted in a male "need" for sexual gratification. Among the responses were: learning about one's own body and exploring one's own sexual possibilities; improving skills in relation to future sexual relationships with non-commercial sex partners; being able to have sexual experiences to talk about with friends – inclusion in male sexual culture; issues related to access restrictions to potential sexual partners; avoiding discrimination; financial constraints – costs associated with dating venues; and the sense of autonomy, agency, control and independence obtained by purchasing the sex work services (Liddiard 2014: 845–849).

Other "alternative" ways of fulfilling the sexual desires of people with disabilities

In addition to the use of paid sexual services provided by prostitutes, there are other forms of assistance to persons with disabilities. Two terms chosen by researchers appear in the literature: "sexual assistant" (Morales et al. 2020; Kessler 2008; Krauze et al. 2010) and "sexual surrogate partner", (Noonan 2007; Rosenbaum 2014), describing different forms of assistance; interchangeably used for the same forms, as well as a combination of the two terms when translating, e.g., "sexual surrogate" (Długołęcka et al. 2013).

Rakić, in my opinion, most accurately points out that, unlike the sex assistant, the sexual surrogate partner is not limited to clients with disabilities, but provides services to those with sexual dysfunctions regarding ejaculation, vaginismus, or with lack of sexual experience (Rakić 2020: 2121).

It is worth recalling other terms that appear in the literature to refer to similar phenomena that differ in nuance from one another: "sexuality advisors", "sexual supervisors", "surrogate partnership", "sex surrogate", "facilitated sex", "intimate accompaniment", "erotic accompaniment", "sexual accompaniment", "sensual partner", and "intimate and erotic assistant" (Gutiérrez-Bermejo 2022: 351). In Denmark, sex workers completing the course receive a sexual adviser certificate; in the Netherlands, sex care is a whole distinct field.

For the purposes of this article, I assume that a sex worker offers his or her services without any prior training geared to the specifics of the disability. A sexual assistant is a person trained to meet the sexual needs of a person with a disability, and differs from a sexual surrogate partner in that there is no additional interaction with the client's therapist, as discussed in detail further below.

Sexual assistant

"Sexual assistance is a sexual accompaniment service for people with disabilities that provides educational services about sexual practices and support services for sexual activity to meet the sensual or sexual needs of clients, bearing in mind the specific characteristics associated with their disability" (Morales et al. 2020: 20). The emergence of the sexual assistant profession stems from the social movements of the 1970s, emphasising the citizen's right to equality. The awakening awareness of the same sexual needs of people with disabilities as those without physical and intellectual disabilities contributed to the emergence, mainly in Europe, of initiatives to promote sexual assistance. In terms of legislation, the legal status of sexual assistance is often identical to legislation covering prostitution.

As Kessler (2008) points out, sexual assistants, unlike sex workers, are distinguished by their training, ongoing supervision, frequency and duration of services, social acceptance of their work, humanistic approach and discretion (Morales et al. 2020: 11). Training and supervision allow for a better "mental balance" than in the case of prostitutes. With regard to people with mobility disabilities, physical assistance may also be necessary, such as undressing, transferring from a wheelchair, e.g., to a bed, helping to position the body appropriately (Długołęcka et al. 2013: 162).

A sexual assistant undergoes a rigorous selection process. Kessler (2008) presents the recruitment process for the first training of sexual assistants operating in French-speaking Switzerland in 2008. Criteria included age of the candidates, who had to be at least 30 years old, relevant qualification documents, including a handwritten letter of application, a curriculum vitae, a certificate of current employment (the candidate was usually paid a minimum of 50% of the total fee for the service), a certificate of morality, a criminal background check, and a registration fee. The second stage was an interview with a practising sexual assistant, and the third stage of the process was reserved for selected individuals. Due to the predominance of men over women among the candidates, it was necessary to limit them, as gender parity was assumed at the outset. According to Kessler, the disproportionality was determined by two factors, the cost of the training, hindering women due to their lower financial autonomy, and the men's freedom of action and power to self-determine outside their homes (Kessler 2008: 54–57).

The training programmes vary in detail from country to country, but are similar to the one conducted in Switzerland, during which, for 300 hours, sexual assistants learn about topics such as: detailed knowledge of different disabilities, legal knowledge, sexuality and sexology in the field of disability, knowledge of corporeality, including body language and eroticism, ethics, institutional contexts, and the role of companions. Additionally, at the end of the programme, supervision is maintained by an experienced worker or a support group to ensure that the sexual assistant is mentally balanced and has emotional support as well as space for reflection and discussion (Morales et al. 2020: 21).

Research on workers' preferences shows that the remuneration of services is secondary to them, the intentions that motivate sexual assistants are the desire to help, altruism, a willingness to provide disabled clients with sexual autonomy and to increase their quality of life as well as their social integration. Services provided to disabled people limited to three or four times a month, not oriented towards maximisation of financial gain, require having a main source of income through other work (Rosenbaum 2014: 325).

Gilard, Muñoz Sastre and Mullet surveyed 238 French respondents about the sexual assistant services provided to physically disabled persons. For this purpose, they used a set of 30 vignettes with different scenarios, concerning the situation of a minor when, being quadriplegic, he expressed his sexual needs to a nurse who arranged an appointment at the hospital with a sexual assistant. The scenarios were developed taking into account the following relationships: gender of the patient x; identity of the assistant (same-sex nurse, opposite-sex nurse, opposite-sex nurse who was trained to be a sexual assistant, prostitute, ex-boyfriend/girlfriend); x attitude of the parent (agreement with the procedure, agreement with the procedure and the assistant's remuneration, disagreement with the procedure). The overall results indicated that 21% of the respondents expressed their disagreement with this type of assistance, 13% were in agreement depending on the identity of the assistant, while 14% of respondents were in agreement providing that payment for the assistance was absent, 8% indicated the need for parental consent, 28% indicated unconditional acceptance, and no specific response was obtained for 17% of respondents. Taking into account religiosity and education, the researchers indicated that male atheists most often always accepted the phenomenon under study, while regular religious practitioners and those with lower education mainly expressed disapproval. Those with higher education and who were also regular observers of religious practice were characterised by an attitude of non-acceptance (Gilard et al. 2019: 109).

The literature is quite scarce on the educational needs of sex care workers offering serviced to people with disabilities. There is also little research on the motivations of people applying to work as sexual assistants. Findings from a study in Italy indicated motivations such as providing assistance to disabled people, enabling disabled people to have sexual experiences, an earning motive, flexible working hours, and support for people with disabilities (Hilberink et al. 2022: 821). A 2021 study among 29 sex care workers found that an important motive of the respondents was that there was not enough attention paid to sexual support for disabled people and that they wanted to make a personal contribution to their sexuality. They indicated a fairly good level of knowledge, with a desire to improve skills in working with clients with mental health problems or autism spectrum disorders, or who had secondary problems caused by physical disabilities. Other aspects included learning to avoid the effort involved in certain positions, and learning boundaries in terms of own sexual pleasure (Hilberink et al. 2022: 831).

Sexual surrogate partner

Sexual surrogate partners are "women and men with professional training who function in place of a non-existent sexual partner during sex therapy using a short-term, limited psychosocial/behavioural therapy model" (Noonan 2007: 1441). According to the recommendations of IPSA (International Professional Surrogates Association), the training of Israeli surrogate partners lasts 40 hours and follows a thorough screening of candidates (Rosenbaum 2014: 323) Typically, the surrogate partner will work with the client, who simultaneously meets with the therapist who directs the client's therapy. Thus, there is a therapeutic triad: client – therapist – surrogate partner. The therapist consults together with the sexual surrogate partner before and after contact with the client. A surrogate partner who does not work with the therapist is considered by IPSA to be outside the professional standards accepted in this type of support.

For legal, ethical or therapeutic reasons, a therapist will not conduct therapy with a person who is in an ongoing sexual relationship or is married. Clients of therapists and sexual surrogate partners are people who are characterised by the presence of sexual disorders, physical or psychosocial limitations. Clients are mainly heterosexual men with sexual and emotional inhibitions or dysfunctions that have prevented or delayed entry into intimate relationships, e.g., childhood abuse, premature ejaculation, erectile dysfunctions, or – for middle-aged men – previous lack of sexual intercourse. Female clients include those with a history of childhood abuse, negative body image, anorgasmia, vaginismus, or sexual shyness.

Noonan's (1984) findings in a group of 54 people indicated that 87% of the professional time of sexual surrogate partners was spent on non-sexual activities such as counselling, sex education (34%), learning social skills (5%), emotional support, sensuality education, relaxation, or self-awareness (Noonan 2007: 1441–1442). Noonan indicates that clients are people with sexual disorders, but does not link them to disability, nor does she link the work of sex care workers to disability support. Compared to sex workers who carry out clients' desires, sexual surrogate partners act according to the requirements of therapeutic goals in cooperation with the therapist (Rosenbaum 2014: 325).

According to Fleckelton (2013), when a surrogate partner's behaviour goes beyond the transmission of information and enters into an interaction involving intimate touch, it becomes a provision of paid sexual services, unless it is an altruistic, non-financial sexual act with a person with a disability, so when there is payment for sexual service we are dealing with prostitution. Due to ethical, legal and clinical issues in considering referral of a client for therapy by a professional, the distinction between the provision of sexual services and sexual surrogate therapy is very important. Prostitution is related to financial gratification for engaging in a sexual act, the aim being the sexual gratification of the client. Sexual surrogate therapy does not necessarily focus on sexual gratification, stimulation or intimate touch, instead the partner focuses on helping clients build social and physical self-awareness, as well as awareness and skills related to physical and emotional intimacy, therefore it is about learning healthy intimacy. As Fleckelton points out, the aspirations of sexual surrogate therapy services are lofty, focusing attention on holistic goals, not just on penetration or other sexual interactions. Looking at the financial side, gratification takes place every time, as with prostitution. When giving an assessment of the legal situation, it equates sex replacement therapy with prostitution. Local Australian law regulates the existence and supervision of brothels, establishes licensing, hygiene controls, underpinned by, among other things, the idea of protecting the physical health of clients. Thus, in order not to break the law, a sexual surrogate partner should participate in the licensing system in order not to expose themselves to criminal liability associated with illegal prostitution (Fleckelton 2013: 651–652).

The researchers point out that there is little data for evaluation of the effectiveness of therapy with surrogate partners, especially presenting results without a control group. Masters and Johnson (1970) believed that therapy was effective in 63% of men with primary erectile dysfunction and in 78% with secondary dysfunction. The results of Cole's (1982) study indicated that in a retrospective evaluation after 6 months (N=150), which also included 17 women, 73% of the subjects maintained improvement. Subsequent findings (Dauw 1988) indicated that 89% of therapy clients (N=501) had resolved their sexual problems, 5% had partially satisfied their needs, with it being noteworthy that only 6% of respondents had completed therapy. Apfelbaum's (1984) study involving 407 participants indicated that 60% were fully successful, 21% were partially successful, 7% saw no change and 1% experienced a worsening of their situation as a result of therapy. In 2007 (Ben-Zion et al. 2007), a study done in Tel Aviv was published based on data from 16 female clients with vaginismus receiving therapy with male surrogate partners and a control group in which the therapy was conducted with subjects' own partners. All women working with a surrogate partner achieved pain-free intercourse compared to 74% of respondents in the control group. 19% of treatments were interrupted by couple separation. Both groups reported similar levels of satisfaction with the process and outcome of therapy, with women using sexual surrogate partners completing treatment 2 months before women in the control group, which may be explained by a lack of need to engage in relationship dynamics and sexual partner problems (after Rosenbaum 2014: 324).

Legal aspects of sexual services provided to persons with disabilities

While analysing Australian and New Zealand models of prostitution regulation, Crofts and Summersfield (2007: 308) present the following conclusion:

> In order to be effective, the system should reflect a clear licensing model, guided by principles of fairness, transparency, rationality and efficiency. A strict and intrusive registration system is not beneficial to those in the industry or the community. Difficulties in obtaining a licence due to onerous requirements or discretionary granting can lead to the continuation of illegal work and perpetuate poor working conditions for such workers. Licensing models that combine social control and regulation do not necessarily lead to effective regulation of the industry, as indicated by the extent to which certain parts of the industry remain unregulated. This creates the danger of a two-tier system in which much of the industry continues to operate under a criminalisation model (after Sosnowska 2019: 135).

Due to the sexual nature of the work, the position of many countries towards the legalisation of sexual assistance is analogous to that taken towards the phenomenon of prostitution. Where the provision of paid sexual services is permitted and regulated, there is acceptance of sexual assistants, and the prohibition of prostitution is linked to the prohibition of the legal existence of sexual assistance (Morales et al. 2020: 20). However, this is not a rule. An example of this is Sweden, where sex workers are not punished, only clients, but there is no acceptance of sex assistants (Mannino et al. 2017: 500). In the United States of America, on the other hand, where most states treat paid sex work as a crime, sexual surrogate therapy delivered with a therapist has existed since the 1970s. In Germany, where the self-employment of prostitutes has been regulated since 1998, the legal status of a sexual assistant was regulated in 2017 (The Prostitute Protection Act), and in Switzerland in 2008.

In some countries there are services that facilitate sexual engagement for disabled people, e.g., in Sweden, the Netherlands, Denmark, Italy, the UK, Australia, Canada, Japan (Hilberink et al. 2022: 820). Examples of organisations and communities of sex workers or collaboratives for disabled people are the TLC Trust in the UK, Touching Base in Australia, BodyUnity in Switzerland (Geymonat 2019: 2014–2015), Fabs (Welfarr Group Disabled and Sexuality) (Długołęcka et al. 2013: 162), Lovegives in Italy, and APPAS (Association for the Promotion of Sexual Accompaniment) in France (Gutiérrez-Bermejo et al. 2022: 350).

Hilberink, van der Stege, Kelders (2022) point to the existence of five Dutch service providers that facilitate sex work and sex care. Some of the providers identify themselves as specialising in prostitution for people with disabilities, others see sex care in analogy with the rest of the needs associated with clients' disabilities and are opposed to employing prostitutes in the role of helping people with disabilities, as this is a form of professional care. As the authors note, in the Netherlands there is not yet training for disability support workers in the sense of sex care workers, and consideration is being given to using Partner Surrogate Therapy by Masters and Johnson (1970) to provide a framework for training and educational goals and to designate sex care as a legitimate care profession (Hilberink et al. 2022: 820–821).

Ethical aspects and some arguments "for" and "against" sexual assistance

Everyone's successful sex life consists of three factors: sex drive, sexual acts and individual sexuality. For people with disabilities, primary and secondary dysfunctions may occur at each of these levels (Kirenko 2006: 67). Physicians, psychiatrists, psychologists, social workers, therapists of persons with disabilities realise that the sexual needs of their patients/clients are important, and ignoring them is not in line with the concern for the right to sexual expression for all people, stemming for example from the Convention on the Rights of Persons with Disabilities. When confronted with a request for a referral to professionals who can help with an intimate part of a person's life, they may face dilemmas that also arise from the range of legal considerations in a particular country.

The discourse related to sexual assistance for persons with disabilities is in some ways reminiscent of the debate about prostitution in Europe in the past (Wagenaar and Jahnsen 2017) and there is a polarisation of the environment into "for" and "against" sexual assistance for persons with disabilities. Among the "pro-assistance" arguments, there is a vision of skilled, responsible and publicly controlled workers who provide essential services to disabled people with limited opportunities to realise their rights. Opponents view sexual assistance as a manifestation of exploitation, commodification of women and promotion of prostitution. This view ignores the issue of possible male sexual assistance provided to women with disabilities (Geymonat 2019: 215).

The controversy over the role of sexual assistants concerns the boundary between prostitution and the provision of support/care services to people with disabilities (Limoncin et al. 2014, Hilberink et al. 2022, Freckelton 2013). The funding of sexual assistants is also an issue. For example, organisations supporting sexual assistants and clients lobby for state participation in refinancing services and treating them as "prescription sex" (e.g., in Germany). A problematic issue is the provision of sexual services to disabled people that may put clients at risk, without the existence of qualified workers in the support system. The discourse broadened to include the basic sexual needs of people with disabilities touches on legal issues – sexual assistance seen as a way of ensuring one of the rights of people with disabilities.

Situation in Poland

In 1997, amendments to the Polish Penal Code were established. A prison sentence of between 1 and 10 years was replaced by three years of imprisonment for procurement (inducing someone to engage in prostitution), pandering (profiting from someone's prostitution) and facilitating prostitution (for financial gain). Procurement was linked to soliciting prostitution for the purpose of obtaining financial gain. The term "practising prostitution" replaced the previously existing "practising fornication" (Sosnowska 2013: 191). The 2022 amendment to the Penal Code did not change the legal situation of prostitution, which is not punishable, nor is it regulated by law so as to ensure the protection of sex workers in terms of their professional situation or to indicate the rules for the provision of services with regard to the role of service provider and service recipient. The same applies to the role of sexual assistants and unsanctioned sexual surrogate therapy.

Poles have rarely been asked about attitudes to the legalisation of prostitution, so it is not possible to address current social expectations. A survey by OBOP (1994) reveals that 72% of respondents condemn prostitution, 80% of whom were women. 63% of men expressed a negative attitude towards the provision of sexual services, and a lack of condemnation was presented by 32% of men and 16% of women (N=1031). 35% of respondents were in favour of the legalisation of brothels and one in six against, seven out of ten women and 48% of men were against it. In a subsequent OBOP survey (1994), 79% of respondents condemned prostitution, while 16% were for it, and the provision of sexual services ranked sixth out of 18 condemned behaviours mentioned by the researchers (N=980). In a more recent CBOS survey (2021), when analysing Poles' attitudes to such phenomena as having sex before marriage, homosexuality, and the use of contraceptives, among others (as in previous surveys from 2005, 2010, 2013) prostitution was not included among the morally controversial behaviours assessed. Similarly to the CBOS survey (2009) on the assessment of socially reprehensible behaviour, the provision of sexual services was not included.

In terms of the law protecting persons with intellectual disabilities, Article 198 of the Penal Code reads as follows: "Whoever, taking advantage of the helplessness of another person or the lack of ability of that person to recognise the meaning of the act or to direct his or her conduct, leads that person to have sexual intercourse or to submit to another sexual act or to perform such an act, shall be subject to the penalty of imprisonment for a term of between 6 months and 8 years" (Rada

Ministrów [Council of Ministers] 2022). In practice, an intellectually disabled adult consenting to sexual intercourse may be considered a victim of the offence when it is shown that he or she is not aware of a particular act, and the authorities can prosecute the perpetrator without need for the victim to press charges. Thus, in a situation where these persons use the services of a prostitute as well as a sexual assistant, it is likely that under Polish law sexual contact or any intimate activity could be considered as violence. With regard to parents and other persons caring for an intellectually disabled person, we are faced with further considerations, namely whether they could be held responsible for failing to provide assistance in the case of sexual abuse of the mentee or, going further, for participating in quasi-prostitution phenomena (Długołęcka et al. 2013: 185).

According to Polish law, there is therefore no possibility of any organised form of assistance to facilitate access to sexual surrogate partners as exists in select countries. According to the results of the National Population and Housing Census, there were 4.7 million persons with disabilities in Poland, representing 12.2% of the population. Izdebski's 2002 study (N=400) shows that one in five clients paying prostitutes for sex is a disabled person (2012: 585). When evaluating the possibility of paid sex services with state reimbursement for disabled people, if considered as a form of reimbursement as exists in the Netherlands, 63% of British wheelchair users were enthusiastic about such an arrangement (Focus.co.uk 2011). In the same period, Polish disabled people would reject such an offer if it were available to them – 86% of women and 67% of men questioned (Gazeta Lubuska.pl 2012), (after Sosnowska 2012).

Krause, analysing the phenomenon of the normalisation of sexuality and contact with the opposite sex of people with intellectual disabilities, including the obstacles arising from living in Polish residential institutions as well as in family homes, points to such prejudices about the sexuality of people with disabilities as the lack of adequate contraception, the attempt to reduce the risks associated with possible motherhood and entering into permanent relationships, emphasising that there are support solutions already used in other countries. She draws attention to the state support of sexual assistants in the Netherlands in opposition to the avoidance of addressing the issue of disability sexuality in Poland (Krauze et al. 2010: 37–38). In the absence of a broad debate, in-depth research and actions aiming at a comprehensive approach to the sexuality of people with disabilities, including an extensive system of counselling or therapy oriented to the individual needs of the client, it is difficult to state that there is space for discourse and possible sanctioning of the reimbursement of sexual surrogate services presented in the article.

Summary

The sexual needs of people with disabilities who do not realise them within a socially acceptable marriage or permanent relationship are a taboo subject. The use of services offered by prostitutes is quite common due to the lack of available alternatives, but not fully adapted to the needs of people with disabilities (Ślęzak 2016b). Sex care provided by sexual assistants/sexual surrogate partners, on the other hand, is not only difficult to implement, but requires special systemic preparation of the person providing such services as well as the clients, including consideration of financial issues, where the wealth barrier may somehow marginalise the sexual needs of people with disabilities. The role of the sexual assistant or the sexual surrogate partner involves challenges such as defining terms, the issue of stigma that affects sex workers, educational as well as legal challenges, assessing the effectiveness of surrogacy, aspects of funding, ensuring the safety of people with disabilities. This is only some of the issues that were raised. However, Wagenaar and Jahnsen (2017) rightly pointed out a similar polarisation in the discourse that has concerned the phenomenon of prostitution, so it can be assumed that this is only the beginning of a search for a consensus or of development of this phenomenon in general, also in relation to the sexual needs of Polish people with disabilities.

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Social and Spatial Determinants of the Integration of Blind, Visually Impaired and Sighted People on the Example of the Sailing Cruise of the "See the Sea" Foundation

The subject of the analysis is the cooperation between blind and sighted people during a seagoing integration cruise. Integration is understood here as the result of joint sailing activities of people with different visual perception who participated in the cruise on the ship *Zawisza Czarny*. In the text, I put forward the thesis that integration is the result of the readiness of able-bodied and disabled people to create a "common world". Therefore, I conducted qualitative research to verify this thesis. The aim of the research was to identify the factors and principles that favour the social integration of sighted, visually impaired and blind people during a ship cruise. I used primary data from in-depth interviews and secondary data from documentation to analyse social and spatial factors that determine the integration of able-bodied and disabled people during a sea voyage as part of the *See the Sea* project. In the theoretical dimension, the text is based on the assumptions of the integrative model of disability, an important component of which is the concept of the social integration of able-bodied and disabled people.

Keywords: visual impairment, integration of blind and sighted people, seagoing cruise

Introduction

In the natural aspect, the human environment is co-created by the biological and physical properties of the surroundings and the organism within them (Searle 2010; Pietrowiak 2019: 329). Space, which is the basic dimension of everyday life, is one of the fundamental properties of the natural human environment. A sighted person perceives the spatial dimension of life primarily visually (Friedman 2012).

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It results from the biological conditions of the human body and the importance of the sense of sight for the development of the individual, the group, and the man as a species. On the other hand, it is the effect of the socially developed order of perception, which determines the hierarchy of the senses and the rules for their use (Pietrowiak 2019: 205). The way a person perceives the environment is also an element of socialisation and is the basis of a specific *sensorium*, i.e., an embodied model of sensuality (Classen 1990: 722) or "a common, more or less shared pattern of perceiving the world" (Herzfeld 2004: 336). Therefore, the sense of sight has a privileged position in the perception of the environment and its components by modern man, especially a representative of Western culture (Howes 2003; Howes, Classen 2014; Porkertova 2022: 581). The thinking and concept of space and spatiality of a representative of Western civilization are therefore grounded in visual culture (Maseide, Grottland 2015: 594–595).

In the case of visually impaired people, space is not grounded in a visual sense, so they need to "domesticate" an abstract physical space. In the process of "domesticating" physical space, a visually impaired person uses body work and bodily practices as well as supporting devices (Maseide, Grottland 2015: 595). Therefore, in perceptual work (Friedman 2012) aimed at learning about space, bodily possibilities, senses, skills and abilities must be actively used, also taking into account externalised but dispersed cognition (Maseide, Grottland 2015: 595).

Due to visual impairment and limitations related to it, a visually impaired or blind person needs the social environment (Krause 2004: 43) in which the same rights are respected for everyone and appropriate conditions for development are created based on the joint use of social capital and mutual support networks. However, this requires the readiness of all subjects of such a living environment, able-bodied and disabled people alike, to integrate and create a "common world" (Ostrowska, Sikorska 1996; Ostrowska 2015a: 83).

In the text, integration (van de Ven et al. 2005) is understood as the result of joint sailing activities of people with different visual perception who participated in the cruise on the *Zawisza Czarny*. The factors that determine integration understood in this way are as follows:

a) implementation of sailing tasks as part of a mixed watch on the three-masted *Zawisza Czarny* vessel;
b) cooperative division of tasks within the watch and between watches;
c) participation in watchkeeping tasks understood as a component of the sum of work necessary to be performed on a sailing vessel during the voyage;
d) vigilance of cruise participants and mutual consideration of each other's presence and needs during the cruise and port visits.

The subject of the analysis is the integration of blind, visually impaired and sighted people in the conditions of a seagoing cruise, which took place in 2022 as part of the *See the Sea* project. The aim of the paper is to present the social and spatial determinants of the integration of the participants of a seagoing cruise, people with different visual perception.

The presentation of integration factors serves to answer the question: what is the basis for the integration of people with diverse visual perception who make up the crew of the ship? In the theoretical context, I refer to the social model of disability, an important component of which is the concept of social integration of able-bodied and disabled people (Albrecht 1976; Barnes, Mercer 2006, 2008; Ostrowska, Sikorska 1996; Ostrowska 1994, 2009, 2015a; Reindal 2009; Pietrowiak 2019; Whitburn, Michalko 2019).

The concept and models of disability

Disability is associated with difficulty in functioning at the level of the body, in the personal or social sphere – in one or more domains of life (Leonardi et al. 2006: 1220). Difficulties in functioning due to disability force confrontation with everyday life problems and barriers. The basis of the disability experience may be as follows:

a) impairments in the biomedical sense, which result in the dysfunction of some parts of the body (e.g., visual impairment);
b) activity limitations that may hinder performing a given activity (e.g., mobility);
c) participation restrictions in one or more domains of life, which may result in, for example, being excluded from the use of transportation (Ostrowska, Sikorska 1996: 9; Ostrowska 2009: 147; *World Disability Report* 2011: 5; Ostrowska 2015a; Pietrowiak 2019: 326–327).

Disability, as a social phenomenon, is analysed from two different perspectives, which are represented by two models of disability (Albrecht 1976).

The individual model assumes that the problems of people with disabilities are the result of damage or functional limitation of the body (Ostrowska 1996: 9). From this point of view, an individual should undertake actions optimising functioning in society and activities in various spheres of life in accordance with the applicable patterns and social norms. A disabled individual is therefore supposed to adapt to society (Scott 1969; Ostrowska 2009: 148; Goodley 2011: 7–8). Disabled people are treated as a separate social group whose members can meet their needs only within this group. For this reason, the individual model is a separation model, because it assumes that a separate social group of disabled people is a reference system for itself (Ostrowska 2015a: 82).

In the social model, the cause of disability is considered to be an unjust social organisation, emphasising the oppressive and relative nature of normality

(Reindal 2009: 157). From this point of view, it is important to sensitise able-bodied people to the problems of people with disabilities and to transform the awareness of both groups (Ostrowska, Sikorska 1996: 7; Michalko 2002: 52; Barnes, Mercer 2006: 38; Gąciarz 2014: 27; Gąciarz 2015) in the direction of seeking opportunities for their mutual social integration.

The broadly understood concept of integration includes, e.g., the normative, the economic, and the social sphere. Social integration is understood as respecting the same rights for everyone and creating identical conditions for development. In small groups and local communities, it involves equal participation and joint use of social capital. Thus, social integration is based on living with other people and among other people (Ostrowska 2015a: 83).

Defining disability from the social perspective allows to focus on integration activities and social activation of people with disabilities (Niedbalski et al. 2017: 7). The social model is therefore an integrative model, because it promotes the inclusion of people with disabilities in the social systems through adaptation of the socio-material environment such that will allow them to function on an equal footing with other people. In this case, "healthy and fit" people are the reference group for people with disabilities (Ostrowska 1994).

Despite the different starting assumptions of the individual (separation) or social (integration) model of disability, the goal of both models is to improve the everyday life of people with disabilities (with the help of individual rehabilitation or social reforms) (Olivier 1996: 38; Pietrowiak 2019: 325). The models are not mutually exclusive. They are rather complementary theoretical and research perspectives, thanks to which various aspects of the concept of disability can be analysed (Reindal 2009: 156; Pietrowiak 2019: 328).

Due to the differences in the initial assumptions, both models define the ways of social integration of people with disabilities differently. In the individual model, the participation of people with disabilities in small groups or local communities is based on the development of individual capacity for integration. In the integration model, the social and material environment is adapted to the needs of people with disabilities (Ostrowska 2009: 150). A major obstacle in the implementation of the assumptions of the social model may be the awareness barriers (Ostrowska, Sikorska 1996: 7) both of people with disabilities and those with whom these people meet in everyday life. In this context, the readiness of able-bodied people to function "in a common world" with people with disabilities is crucial (Ostrowska 2009: 150). At the same time, the creation of a "common world" by able-bodied and disabled people is a long-term process which requires the social education of both sides of social integration and mutual arrangements to the extent and within the limits integration solutions can serve able-bodied and disabled people (Ostrowska 2015a: 87; Ostrowska 2015b: 233).

Social perception of a disabled person

Representatives of various systems and institutions use different definitions and classifications of disability (e.g., in medicine, law, education). The concepts of disability and disabled person are therefore not unambiguous. What does the term disabled person mean? (Ostrowska 2015a: 59–60). On the one hand, the adoption of the Convention on the Rights of Persons with Disabilities (Rada Ministrów [Council of Ministers] 2012), which Poland ratified in 2012, meant that people with disabilities have equal access to institutions, social activities and roles, just as doable-bodied people (Cotter 2007: 51). In the field of social policy, interpretation of the concept of disability in terms of normalisation is replaced by an interpretation in terms of diversity (Niedbalski et al. 2017: 7). On the other hand, data from panel studies on the perception of people with disabilities indicate that participants of these studies perceive people with disabilities according to four criteria:

a) enumerating various causes, diagnoses and dysfunctions that result in disability (e.g., the blind);
b) indication of functional limitations (blind people);
c) based on legal qualification (persons who have a certificate of disability);
d) from a visual point of view (e.g., persons with visible bodily damage).

Generally, however, the group of people with disabilities is perceived by the respondents of these studies primarily according to medical criteria through the prism of a defect, disease or damage. In public perception, a disabled person is typically a person in a wheelchair. A disabled person, who is socially integrated, is a person with relatively milder forms of limitations in functioning, and this image of a disabled person dominates the term "disability" (Ostrowska 2015a: 61–63).

The ambiguity of the concept of disability and the diverse perception of a disabled person, e.g. due to various physical and social limitations of disabled people, make disability appear as a relative concept. Therefore, fitness and disability can be considered as two poles of a continuum on which both able-bodied and disabled people can be situated. In practice, placing someone on such a continuum depends on a set of various factors: medical, socio-cultural, political and economic (Ostrowska, Sikorska 1996: 8). Referring to the assumed context regarding the concept of fitness and disability, I will present:

a) dimensions and conditions of integration between able-bodied and disabled people on the example of a cruise on the *Zawisza Czarny* as part of the *See the Sea* project;
b) aspects of the readiness of people with diverse visual perception to implement the postulate of creating a "common world" during a seagoing voyage.

Methodological assumptions and description of the research sample

From 2006 to 2016, seagoing cruises with the participation of people with different visual perception (blind, visually impaired and sighted) were held as part of the *See the Sea* project. They were initiated by Roman Roczeń (a blind person who was a participant of standard cruises), Captain Janusz Zbierajewski (the first to decide to conduct a cruise with half the crew with visual impairment) and Robert Krzemiński (then a member of the management board of one of the corporations, a crew member of the first cruise in 2006 and later in the years 2007–2022 – the main organiser) responsible for the logistics of the cruise. Since 2016, a seagoing cruise has been organised by the Tomek Opoka *See the Sea* Foundation (Roman 2016).

The analysis of integration between blind, visually impaired and sighted people during a cruise is a result of my research conducted from November 2022 to January 2023. The participants of the cruise on the *Zawisza Czarny* of the two dates were invited to the study:

a) first cruise: 27 August to 03 September 2022;
b) second cruise: 03 – 10 September 2022.

On the first date, 35 crew members participated in the cruise.

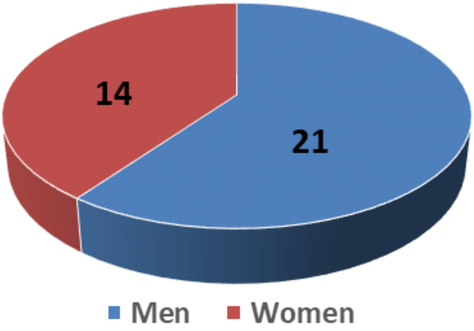

Figure 1. Division of the participants of the first cruise by gender

Source: author's resources based on own research.

On the second date, 32 crew members participated in the cruise.

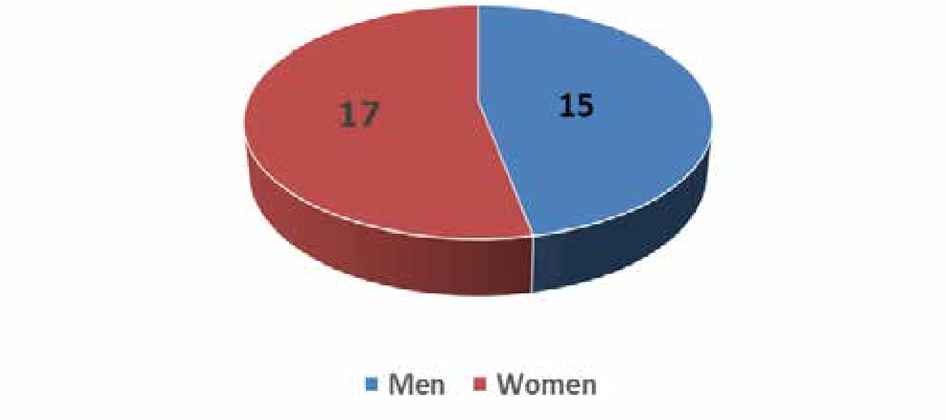

Figure 2. Division of the participants of the second cruise by gender

Source: author's resources based on own research.

The participation of a given person in the cruise in 2022 was the criterion for selecting subjects for the research sample. 12 people (5 F and 7 M), who participated in the cruise on the first date (27.08–03.09.2022) and 11 people (7 F and 4 M) who took part in the cruise on the second date (3.09–10.09.2022) accepted the invitation to be interviewed as part of the study; two people [1 F, 1 M] participated in both editions of the cruise.

Table 1. Characteristics of the respondents of qualitative interviews (IDI)

Respondent's number	Sex	Age	Education	Place of residence	Vision condition
1.	f	22	Secondary	Godzięka, Gniewkowo	Sighted person
2.	m	25	Secondary	Konradów	Blind person
3.	m	28	Higher	Cracow	Blind person
4.	f	28	Secondary (technical)	Warsaw	Blind person
5.	f	31	Secondary	Hamburg	Sighted person
6.	m	31	Higher	Cracow	Blind person
7.	f	36	Higher	Warsaw	Sighted person
8.	m	36	Vocational college	Gdynia	Severely visually impaired person
9.	f	37	Higher	Toruń	Sighted person

10.	f	38	Higher	Nysa	Sighted person
11.	f	40	Higher	Sosnowiec	Visually impaired person
12.	m	40	Secondary (general)	Gdynia	Visually impaired person
13.	f	42	Higher	Gdynia	Monocular person
14.	m	44	Higher	Grodzisk Mazowiecki	Sighted person
15.	m	46	Higher	Siemianowice Śląskie	Sighted person
16.	f	46	Higher	Gdańsk	Sighted person
17.	m	47	Secondary	Wilczyce	Sighted person
18.	f	47	Vocational college	Piekary Śląskie	Blind person
19.	m	47	Higher	Suwałki	Sighted person
20.	f	51	Vocational education	Drwęck	Monocular person
21.	m	54	Secondary (technical)	Pabianice	Sighted person
22.	m	64	Higher	Warsaw	Sighted person
23.	f	67	Incomplete higher (vocational college)	Warsaw	Blind person

Source: author's resources based on own research.

The work organisation of the *See the Sea* Foundation is oriented towards the implementation of the subjective and causative concept of social activities. In accordance with this concept, I assume that individuals are creative beings. The readiness to create a "common world" of able-bodied and disabled people (Ostrowska, Sikorska 1996; Ostrowska 2015a) may therefore inspire them to design and experiment with different variants of solutions that may foster integration (Lofland et al. 2006: 166). I assumed that conversations with the participants of a seagoing cruise would help me to identify the social and spatial factors of integration in the individual and collective dimension. Therefore, I asked the organisers of the cruise for help in reaching the participants and obtaining their consent to participate in the qualitative study. After obtaining the consent, I conducted in-depth qualitative interviews by telephone (Miller, Glassner 2004: 125–139; Lofland et al. 2006: 148–158). The conversations with the cruise participants provided the original empirical data on the participation in the voyage and the social world created under these circumstances (Holstein, Gubrium 2004: 140). The primary data was supplemented with the data available on the website of the *See the Sea* Foundation and the visual data, i.e., photographs provided by the cruise organiser.

23 people (12 women and 11 men) participated in the interviews, including 12 sighted people, 3 visually impaired people, 2 monocular people, and 6 blind people.

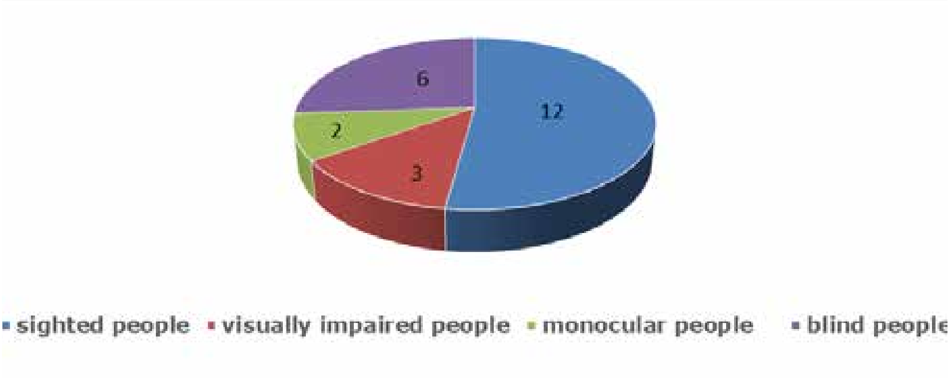

Figure 3. Division of the respondents participating in the cruise based on the degree of visual impairment

Source: author's resources based on own research.

The respondents included cruise participants (21 people) and permanent crew members (2 people). This allowed me to compare different perspectives of the participation in the cruise. The telephone calls lasted from 20 to 60 minutes.

The agenda of the interviews covered the following topics:

a) motives and preparation for participation in the cruise;
b) spatial determinants of integration (properties of ship architecture, weather conditions);
c) course and organisation of work during watchkeeping tasks from the perspective of visually impaired and sighted people;
d) course and organisation of the stays in port (e.g., the way of sightseeing);
e) self-assessment of participation in the cruise.

The research problem was the search for an answer to the question: what social and spatial factors determine the process of integration of people with diverse visual perception during a seagoing cruise? The aim of the research was to identify the factors and principles that favour the social integration of sighted, visually impaired and blind people during a cruise. Empirical data from the interviews were analysed using the focused coding procedure (Lofland et al. 2006: 200–209), for which MS Office tools were used. In the analysis of the content of the interviews, the fragments that characterised and explained the concept of integration were marked and coded (van de Ven 2005: 316). The codes corresponding to the elements of the concept of integration were the basis for the analysis of the factors determining integration of the crew on the *Zawisza Czarny*. The photographs were also taken into account in the focused coding procedure. They are a means of recording and presenting information, and therefore they were treated as a code sheet (Emmison 2004: 251).

Social determinants of integration of the crew members with differentiated visual perception

Aspects of interpersonal integration: planned and natural integration

The *See the Sea* Foundation organises seagoing cruises for people with diverse visual perception. In this way, the Foundation wants to integrate able-bodied and blind people as well as the surroundings of people with visual impairments (Powersport.pl [n.d.]).

Zobaczyć Morze

Zobaczyć Morze to projekt, który powstał w Polsce i trwa nieprzerwanie od 2006 roku. W skali światowej jest unikalną inicjatywą mającą na celu integrację osób z dysfunkcją wzroku poprzez organizowanie pełnomorskich rejsów. Załogę zawsze w połowie stanowią właśnie osoby z dysfunkcją wzroku. Dzięki temu realizuje się dwa ważne cele: rehabilitację poprzez czynny udział w pracy i życiu na jachcie oraz integrację z osobami pełnosprawnymi. Do tej pory blisko pół tysiąca niewidomych i słabowidzących mogło wziąć udział w morskich wyprawach.

See the Sea

See the Sea is a project which was started in Poland and has been running continuously since 2006. On a world scale it is a unique initiative aiming at integration of the visually impaired through seagoing cruises. It is the visually impaired who represent half of the crew. This allows achieving following goals: rehabilitation through active participation in life and work on the sailing yacht and integration with non-disabled people. So far nearly 500 blind and visually impaired people could participate in the seagoing cruises.

www.zobaczycmorze.pl

Photo 1. Synthesis of the assumptions and effects of the *See the Sea* project

Source: private collection of the Captain A.B. Emche of the *Zawisza Czarny*.

In 2022, the integration cruises were held in two stages: 27.08–03.09 and 03.09–10.09. From the formal point of view, the process of integrating the participants of the seagoing cruise began with the creation of the list of people qualified for the voyage. From that moment, the participants could communicate in matters related to the preparation and participation in the cruise.

People were arranging who was travelling with whom (…). There was an option that if accommodation or transport from the train station was needed, we agreed to help so that no one would be left alone (Iwona, a sighted person). … *We all had telephone contact, we exchanged telephone numbers. The person called, we went out and took this person to the ship* (Marcin, a sighted person).

The planned organisational activities (e.g., embarking) intertwined with the activities that the cruise participants had to undertake *ad hoc* in order to meet their basic existential needs (e.g., overnight stay before departure from the port, because the cruise participants arrived at the port of departure from different places in Poland and abroad) or due to unexpected events (e.g., out of order toilets on a ship).

During the first cruise (27.08–03.09.2022), several people reached Gdynia the day before departure. For this reason, they could earlier join the loading of provisions onto the ship. … *We arrived a day earlier and (…) we slept on 'Zawisza' (…). First, we helped with boarding, because some water and juices were still unpacked (…), we helped unpack them* (Karolina, a blind person). Participation in the loading of provisions helped the participants of the cruise, who had arrived early, to begin integrating with each other and with the members of the permanent ship crew.

During the second edition (03.09–10.09.2022), the cruise was delayed by one day. For this reason, it was necessary to make things work until the ship departure and meet the basic needs: *We sailed a day later (on Sunday). (…) It turned out that some people came from far away and needed something to eat. Going out (…) was the first contact with the blind people. Everything had to be said (…). I felt needed. There were more blind people than sighted people. This event integrated us* (Iwona, a sighted person).

The delay of the ship's departure triggered spontaneous behaviours that allowed us to get to know each other. … *We went for a walk and everything went off without a hitch. The walk made it easier to get to know each other. First, within a narrower group: 2–3 people* (Agnieszka, a one-eyed person).

In the phase of preparation for embarkation, subjective integration occurred in small social systems, and was a derivative of the integration assumed by the cruise organisers.

The process of integrating the cruise participants was shaped, on the one hand, by the organisational activities planned by the Foundation (social integration assumed by organisers), and on the other, by natural circumstances that inspired the cruise participants to build social relations (natural integration).

The toilets didn't work, so there was a problem, but the organisers arranged the toilets for us (…) a bit further. (…) It was natural that if someone said – I'm going to the toilet, who goes with me? – a number of people replied (…), and then we needed a sighted person to lead the group. While waiting for the ship to sail, it was also possible to integrate on land as part of the previously created watch. *The watch officer said that since we were not sailing we were going for a beer. The people immediately started to organise themselves: who is going with whom, who is leading whom so that it would be safe* (Iwona, a sighted person).

The participants of the cruise were divided into watches according to the principle: half of the blind or visually impaired and half of the able-bodied so that they could jointly perform seafaring tasks (Powersport.pl [n.d.]). The division of the participants based on differentiated visual perception implies the communication principle of adequate description of the static and dynamic properties of the environment in which sighted, visually impaired and blind people live together. The clock code is helpful in this context. Sighted people use it to help visually impaired people reach a specific point on the ship or to find out where utility items are located. Thanks to this, when blind people receive information from sighted people, e.g. *that the entrance to the toilets is at the exit of the forecastle at ten to one…* (Jacek, a sighted person), or … *when you are at the table, at 12.00 you have butter, at 01.00 you have bread, at 04.00 you have sausage* (Aleksandra, a sighted person). In this way, they can get from point A to point B or perform activities more efficiently.

In the relationship between the watch officer and a crew member, the officer must adequately convey instructions to the blind: … *The instructions must be such that the blind person gets clear information (…) where to go and what to do* (Andrzej, a sighted person). Sighted people had to take into account the requirements of the situation and correct their habits during communication with blind people. … *As a rule, at the beginning you feel embarrassed, you need to help the blind, but not to do for the blind, you don't know what to do* (Dariusz, a visually impaired person). … *Explaining the concept: pull – loosen, is a bit abstract for them* [visually impaired people]. *(…) It was instinctive to help, to do it, but we had to withdraw from it quickly in order to give them* [people with visual impairments] *a chance* (Iwona, a sighted person). As for communication, it is helpful to recognise mutual expectations. Therefore, one of the sighted people encouraged the visually impaired to inform them if they made a communication error: … *Tell me when I make a mistake, because I need to learn how to help you* (Jacek, a sighted person).

The conditions of a cruise allow participants with visual impairments to come into contact with the open sea and sailing. However, the organisers of the cruise offer an active form of contact with sailing, which requires the participants' full involvement in on-board tasks, because … *the point is for people to get acquainted with life on the ship* (Henryka, a blind person). Therefore, participation in a cruise is a full-fledged sailing. … *I wasn't convinced that I would actually be a full-fledged sailor there. I found out about it already on the ship and during the cruise…* (Radosław, a blind person). … *At first, it seemed that the crew would appear and someone would do everything for us. It turned out that everyone had to carry out their responsibilities…* (Paweł, a sighted person).

The crew's duties also include steering the ship. This is the task that most impresses those who have not experienced it.

It goes like this. There is a vertical steering wheel and you have to turn it. We have voice messages for the blind (...), what is the course, what is the degree of deviation and you have to direct the wheel (Henryka, a blind person). *The position of the rudder and compass is indicated by the so-called chatterbox, an electronic device that reads the position of the rudder and the compass and gives this information to the helmsman's ear, and the blind helmsman steers the ship, which is 46 metres long and has a crew of 40, and we are all in his or her hands* (Andrzej, a sighted person).

Task integration of crew members during the cruise

The purpose of the cruise was to integrate the crew in the subjective (interpersonal) and objective (task) dimension. However, the pace and scope of task integration depend on the sailing experience of cruise participants. Among the respondents, 18 people participated in a cruise for the first time. For 5 people it was at least the second time they took part in a cruise. 16 people had a greater or lesser amount of sailing experience whereas 7 people had never gone sailing before. The organisation of work on a three-masted sailing ship allows people without sailing experience to participate in a cruise. … *the 'Zawisza Czarny' is a vessel that does not require climbing the masts or yards to raise or lower the sails* (Aleksandra, a sighted person). Therefore, the lack of sailing experience and visual impairment do not limit the cruise participant in the performance of tasks, providing that it does not interfere with the general principle of safety and smooth work on the ship.

When selecting crew members, cruise organisers try to balance the composition of the watch in various respects. Therefore, they take into account the following factors: the number of people who sail again, the number of participants with visual impairments, mobility limitations, gender distribution, and sailing experience. There is always a person on watch who has been to sea before (in the community slang – the so-called recidivist) … *they know the ship and have sailing experience.*

(…) If we have more such people, we put them on watch so we have a leader among the blind who will facilitate the work of other blind people (Andrzej, a sighted person).

People who are sailing again help participants who sail for the first time get to know the ship and the tasks to be performed, they share their knowledge. *… I helped some people to take their first steps. When I sailed for the first time on 'Zawisza', I used my eyesight a bit. I have a very good memory and not much has changed over the years, so now it was much easier for me* (Tomasz, a blind person). This is one of the aspects of assumed integration because people who sail for the first time are to varying degrees socially rehabilitated. People who sail again are a kind of determinant of how individual or social barriers can be overcome *… our example allows them to overcome their barriers, because they see that if we manage, they can too…* (Tomasz, a blind person).

Sailing tasks were implemented within a mixed watch on the basis of a cooperative division of tasks. There was a rotational division of tasks (e.g., work in the kitchen, cleaning the deck, navigation), which all participants had to perform on their watches. 42 people (cruise participants and permanent crew members) took part in the sailing cruise: Gdynia – Kalmar – Hel – Gdynia. This required cooperation throughout the entire voyage. Therefore, e.g., a watch consisting of a blind person, 95% visually impaired, a person with combined visual impairment and mobility limitation, the division of work and implementation of tasks were proposed by able-bodied people: *… we had to take care of each other and that was the goal of this project. We tried to engage them in absolutely everything we did, i.e., cleaning, washing dishes, cooking, yacht steering. It turned out that it was possible (…). If we divided: a visually impaired person or a blind person plus a sighted person, then (…) we were able to efficiently work in pairs, teams (…). It was not an obstacle for us to go from point A to point B, peeling potatoes, preparing meals (…), steering. We were so dependent on each other that we managed to work together* (Kinga, a sighted person).

The example of the watch illustrates the approach of sighted people and confirms the readiness of people with different visual perception and mobility to create a "common world" during a seagoing voyage. In this context, able-bodied people adopted the perspective of a different ability (Krause 2004: 41) of disabled people and agreed with them on the manner and type of tasks to be performed. On this basis, people with sight or mobility disabilities participated in the jointly defined on-board work.

During the voyage, the implementation of sailing tasks on the mixed watches was based on the principle of symmetry, which favoured subjective and objective integration. This is illustrated by the following statements of sighted and blind people and the photo below:

Table 2. The division of work during the voyage according to sighted and blind people

The sighted person's perspective	The perspective of a blind person
Every action required cooperation. A handful of sighted people would not be able to cope alone (Barbara).	*All tasks on the ship require the cooperation of blind and sighted people. The blind would not be able to cope alone* (Henryka).
They supported each other in every situation. No one was singled out (…). Everyone was assigned tasks and performed them very well (Paweł).	*It was necessary to cooperate in order to perform tasks well, efficiently and quickly* (Radosław).

Source: summary based on own research.

Photo 2. The principle of symmetry in the implementation of sailing tasks
Source: private collection of Captain A.B. Emche of the *Zawisza Czarny.*

During more difficult weather conditions, due to safety reasons, onboard tasks were performed mainly by sighted people. In a situation where, for example, a larger number of people were unwell due to seasickness, crew members from other watches helped. Inter-watch cooperation was an opportunity for inter-watch integration. This integration accelerated the performance of tasks such as: lifting booms, loosening and pulling the sails, clearing the sails, tying the sails with sail stops. *This work would take an hour, not half an hour, if we only did it as part of the watch* (Radosław, visually impaired person).

The cruise also allows participants with visual impairments to come into contact with maritime culture. Therefore, during the port call (Kalmar/Karlskrona), cruise participants go ashore to, for example, visit a shipping museum or historic places related to the sea (Powersport.pl [n.d.]). Sightseeing is an opportunity for social integration on land. Blind, visually impaired and sighted people must work together to reach the destination and communicate intensively during the visit. … *We went to the maritime museum. I guided a blind girl, she held my arm and I told her what I saw, along with the story of this place. I have never visited any museum so thoroughly before. You have to tell what is going on so that the person can build the picture in their imagination…* (Jacek, a sighted person).

Spatial determinants of integration of cruise participants with differentiated visual perception

The physical space of the ship

Zawisza Czarny is the successor to the yacht of the same name, on which Polish scouts were taken to sea in the years 1935–1939. In 1960/61, it was converted from a type B-11 fishing lugrotrawler named *Cietrzew*. After its reconfiguration, *Zawisza Czarny* had a lowerdeckhouse, a ballast ledge and three masts. Living quarters were created in the former hold. In the years 1979–1980, the deckhouse was replaced with upper works. Training cruises for scouts, people with disabilities and socially excluded youth as well as integration cruises were or have been held on the ship as part of the *See the Sea* project (Maracewicz 2013: 6, 8–9). In the years 2016–2018, onco-cruises for people with oncological disease were held on *Zawisza Czarny* (Onkorejs.pl [n.d.]).

In the case of the *See the Sea* integration cruise, crew members, who are physically and perceptually diverse, learn about the ship structure through personal mapping and with the help of the watch officer.

Photo 3. Ship exploration by touch

Source: private collection of Captain A.B. Emche of the *Zawisza Czarny.*

Before the voyage, the officer familiarises the watchmen with the ship and the tasks they will perform. … *Each officer takes his/her watch, they must be trained in raising and lowering the sails, there is also a tour of the ship* (Aleksandra, a sighted person). … *The first thing they did was to show us around the ship, they show you your bunk so that you know where to go, where the toilet is, where the shower is, as well as the galley or kitchen* (Marcin, a sighted person). … *We got to know the topography of the ship being on the ship (…). We could get to know it on our own or with the officer, we were shown our mast, ropes, because there are a lot of them, so we learnt the nomenclature…* (Dariusz, visually impaired person). … *Everyone, at their own pace, brailles the sailing ship, in their own way* (Aleksandra, a sighted person).

The ship existential space

We can consider the space of the ship from the physical and existential point of view. As soon as the crew members appear on the ship, the physical space of the ship becomes the space of their existence (Maseide, Grottland 2015: 596). Therefore, in order for visually impaired people to be able to safely move around in the closed space of the ship during their one-week stay there, a security system made up of ropes and railings is needed.

Photo 4. The physical and existential space of the *Zawisza Czarny* ship

Source: private collection of Captain A.B. Emche of the *Zawisza Czarny.*

The efficient mobility of a visually impaired crew member in a space managed by sighted people (Maseide, Grottland 2015: 595) also depends on how their sense of orientation is shaped. The safe movement of a person with visual impairment or mobility limitation on the *Zawisza* is therefore determined by objective factors (e.g., life-saving ropes and railings), but also subjective elements, e.g., sailing experience and the sense of orientation. A more well-developed ability to orientate helps to navigate more efficiently in the confined space of the ship.

I knew I had to get to the railing (to grab something) and then I go ahead… this way I will always get somewhere. The limited space helps a lot. Limited by something to which I can attach myself and go ahead, or go on a track I know (Radosław, a blind person). In the case of a visually impaired person, navigating the ship existential space is based on embodied memory. Such memory is inherent in a person's body as it recreates the past (Casey 1987: 148). It allows the blind to practice spatial habits (Maseide, Grottland 2015: 596).

A less well-developed sense of orientation may hinder the mobility of a blind person on a ship. … *Some have good orientation, others a little worse. Ropes show the way on board. There are no more ropes below deck. There were tables, steps. The step was on one side and on the other. If I made a mistake, I hit the step, but I didn't hit my bed…* (Henryka, a blind person). Difficulties with orientation meant that the ropes and railings, as components of the existential space, were not enough to reach the destination flawlessly, which resulted in getting lost. Then the presence of other people, who could lead to the goal, was important. … *I happened to get lost, but there was always someone who guided me. There was no fear that I would hurt myself…* (Henryka, a blind person).

Sighted people build their vision of the ship based on what they see, because the sense of sight allows them to scan any space. At one moment, they can take in the field of view or exchange glances with other people to coordinate spatial interactions (Maseide, Grottland 2015: 598). Blind and visually impaired people, on the other hand, map the ship differently, that is, they explore the physical space of the ship and become familiar with its architecture more through touch, which allows them to perceive the ship space tangibly on a real scale, or they get to know the ship on a smaller scale based on a model of the ship, which is available aboard *Zawisza*. … *We had a model of the 'Zawisza' ship, with relatively movable elements of the sails* (Marcin, a sighted person). The use of touch in spatial perception causes the perceptual horizon of a visually impaired person to be shorter than that of a sighted person. Tactile perception is also more laborious, time-consuming and energy-intensive than visual perception (Maseide, Grottland 2015: 598).

From the perspective of a sighted person, the architecture of the *Zawisza Czarny* is not easy for people with visual impairments or mobility limitations. In the deck part, from the forecastle to the stern, the surface is even, but … *from the forecastle to the bow it goes slightly up* (Jacek, a sighted person). The deck of the middle superstructure (quarterdeck) and the descent to the galley may cause difficulties for a person with reduced mobility and visual impairment, because … *if you want to get to the toilet, you have to climb steep stairs. Then you have to come down. If you go to watch, you have to go up the quarterdeck, then you have to get off it* (Iwona, a sighted person).

In the crew part of *Zawisza Czarny* there is a room (forecastle) where the entire crew sleep. The crew sleep in layers (on three or four bunk levels), … *they always eat and work together* (Andrzej, a sighted person). … *There is no division into cabins* (Aleksandra, a sighted person). Such a structural solution favours subjective integration, although it may be surprising at first for a person who is not used to tight spaces. … *I boarded the ship and we went to the cabin which is the place where you sleep. We were shown our bunks and I took my things there, I had this first moment: Oh my God! I don't want it, it will be terrible, it is so cramped there and there is so little space (…) and so many people will sleep in one room* (Karolina, a blind person). Crewmen must therefore take into account the specificity of such a solution, because … *in a situation where everyone is in one room and sleep in layers… in the forecastle, everyone participates in the whole life of the crew. (…) This has its disadvantages, of course, but here it is an advantage. (…) Like it or not, everyone participates in the whole life of the crew* (Andrzej, a sighted person). *Basically, the specificity of the 'Zawisza' forecastle promotes… integration, making friends…* (Henryka, a blind person).

The crew members use the security system during the cruise (ropes, railings), which supports people with visual impairment against losing control or getting lost while moving around the ship. Life-saving ropes are stretched between strategic points, e.g., from the forecastle to the bathroom or from the forecastle to the kitchen. The ropes protect against loss of control, especially when weather conditions are bad. The ropes are also run along the sides, on the gunwales. All the ropes help visually impaired people find their way around the ship more easily. Protection for the crewmen included harnesses, shoulder and chest braces with a metal buckle to which the noseband with snap-links are attached so they can be attached to the steel life-saving rope or other permanent elements of the ship. For safety reasons, the crewman must remain fastened to life-saving ropes during the day when there are bad weather conditions and after the sun sets. The exception is working in the kitchen, because the space in the galley is narrow and braces can make it difficult to work there. The permanent crew of the ship repeats that people with visual impairments should help themselves with their hands according to the rule: *one hand is for you and the other – for the ship, which means that we always use one hand to secure ourselves and hold something stable…* (Karolina, a blind person) *or* at the entrance into the room, *one… hand protects the head, the other hand holds a life-saving line or handrail…* (Jacek, a sighted person).

Summary

Integration, which in the text is understood as the result of the readiness of able-bodied and disabled people to create a "common world", implies identification of social and spatial factors determining this process during the sea voyage under the auspices of the *See the Sea* project. The results of the qualitative research indicate that in the spatial dimension, the integration of sea voyage participants was determined by the characteristics of the ship architecture (e.g., a specific area of the forecastle, or an enclosed space of the ship), security system (ropes and railings) that allowed all participants to move safely in the enclosed spaces of the ship, and by weather conditions (e.g., the sea state, wind velocity).

In the social dimension, the integration of sighted, partially sighted and blind people was shaped by the principle of dividing the participants into mixed watches, which were proportionally made up of blind, visually impaired, and sighted people. Such a division was a kind of challenge that the participants of the cruise had to take to build social integration based on sailing activities. For most of the cruise participants, it was the first time they had met one another. Because they were not yet acquainted with other members of the watch, it was difficult to predict how their cooperative activities would work out. Sailing tasks, however, require cooperation, therefore the crew must work together in order for the ship to sail. Social integration of the cruise participants was determined, on the one hand, by organisational activities planned by the Foundation (assumed social integration), and on the other, by natural circumstances that inspired the cruise participants to build social relations (natural integration).

The division of the participants based on differentiated visual perception implied the communication principle of the adequate description of static and dynamic properties of the environment in which sighted, visually impaired and blind people lived together. Individual people in four watches had a sum of work to do, which they divided depending on their capabilities and weather conditions. Each person in the watch had a chance to contribute to the total amount of work necessary to be done on the ship. Joint work in the watch, as a practice used in the maritime culture, integrated the *Zawisza* crew in the task aspect.

This corresponds, for example, with the results of the study conducted by Dutch researchers, whose aim was to determine the factors that, according to people with disabilities and their relatives, favour integration. From their perspective, integration is the result of joint functioning in mixed social systems of people who are not indifferent to each other and contribute to social life using available opportunities (van de Ven 2005: 316).

However, the diversity of watch members in terms of their visual perception and mobility made it necessary to define the rules for the implementation of watch tasks. Therefore, task integration of the cruise participants was the result of work organisation based on the following principles:

a) considering each other's presence and needs as appropriate;
b) symmetrisation of task cooperation in the watch and, if necessary, cooperation with persons from another watch.

All crew members cooperated during the integration cruise. Therefore, people without sailing experience learned all the sailing tasks on an ongoing basis. The *See the Sea* project combines the theory and practice of sailing. The efficient combination of theory and practice results from the fact that the cruise organisers try to balance the composition of the watch when selecting crew members. For this reason, the watch also includes a person who has been to sea before. Such a person helps participants who are going to sea for the first time to familiarise themselves with the ship and with the tasks that are to be performed, and who freely shares his/her knowledge. Visual impairment and lack of sailing experience do not limit the cruise participant in the performance of his or her tasks, as long as there is no threat to the safety of the crew and the smooth carrying-out of the work aboard ship. A person with disability and a non-disabled person may equally and jointly take part in any sailing task. This allows them to take into account their own diverse perspectives and, on this basis, discover why they need each other. As a result, this integration solution is beneficial for both sides of the process (Ostrowska 2015a: 87; Ostrowska 2015b: 233).

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Cultural Idioms of Distress as an Example of the Social Distribution of Health – The Case of Javanese *Ngamuk*

The aim of this article is to look at the phenomenon of the social distribution of health in terms of differences in the relative perception of diseases, including their symptoms. The author presents this phenomenon using the example of *ngamuk* illness. It is considered to be characteristic of Javanese culture, similar to *amok*, characterised by extreme physical aggression (including homicide). The empirical basis for this article is the results of an ethnographic field study conducted in the grounded theory strand in Yogyakarta, Indonesia, in 2019–2020. The data come from 31 individual in-depth, semi-structured interviews on the cultural image of mental illnesses. Western medical practitioners, traditional healers and students participated in the interviews. What emerges from the Indonesians' statements is the social image of largely the mentally ill person as one who displays aggressive behaviour towards others, including murder. The results indicate that although none of the interviewees used the word *ngamuk* when describing mental illness, the symptoms cited were close to the symptomatology of the disorder. Juxtaposing the results with other studies in the field of cultural perceptions of illness, the author concludes that the social perception of mental illnesses is strongly culturally-relativised. This also means that the view of illnesses is socially distributed, as exemplified by *ngamuk*.

Keywords: mental illness, *ngamuk*, Indonesia

Introduction

The social distribution of health is sometimes viewed as a phenomenon of inequalities related to morbidity, the course of illness or the presentation of symptoms. This phenomenon can also be considered in a different way – as disparities in the relative perception of illness. Differences in identifying and talking about symptoms of mental illness are the subject of this article. In the study, I analyse

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which symptoms of mental illness are talked about by Indonesian Javanese people and to what extent one can talk about the perceived prevalence of *ngamuk* in this cultural circle. The text looks at Indonesian society and outlines the symptomatology of mental illness in other cultures, in particular the phenomenon of culturally determined illness. I consider how the results of my empirical study can be related to previous reports of *ngamuk* morbidity in Java. I provide some examples of the different symptomatology of mental disorders across cultures, discuss and debate the concept of cultural idioms of distress, and present the results of my own research conducted in Indonesia, considering how they relate to the phenomenon of the social distribution of health. I show to what extent culture matters in perceiving, assessing and describing health and illness.

An anthropological view of health

The study of the social distribution of health is closely linked to anthropology, as this discipline recognises health and illness as culturally-relativised phenomena. Medicine is a system of symbolic meanings embedded in the conditions of social institutions and patterns of interaction. Not only patients, but also physicians and healers are entangled in a system of cultural meanings and placed in specific configurations (Kleinman 1980). According to Kleinman, the health care system is formed by collective beliefs and shared practices operating at the local level. This system is perceived and used differently by individual social groups, families and individuals (Kleinman 1980). The beliefs and behaviours that constitute symbolic activities within the health care system are influenced by social institutions (e.g., hospitals, trade unions), social roles (e.g., physician), economic and political constraints as well as other factors, in particular available treatments and the type of illness (Kleinman 1980). The phenomenon of illness perception is aptly summarised by Fabrega: “Beliefs about illness are thus examined in terms of the cultural themes and organised behaviours of the group. An underlying assumption of course, is that the group does not share the prevailing Western biomedical view of disease and medical care” (Fabrega 1974: 4). The perception of diseases is thus closely linked to the beliefs found in the community (Twaddle 1973: 753).

Even between groups within the same society, different perceptions of mental illness can be observed (Brodniak 2000). These differences become even more apparent when comparing Western cultures to more distant ones. Non-Western cultures are characterised by greater collectivism, which is also reflected in the perception of the mentally ill by those around them. A study in China showed that conditions that are described as mild mental problems in Western psychiatry are not classified as mental health-related as long as they do not impact relationships with family, neighbours or friends. They have often been seen as stemming from difficulties functioning in a collective culture – for example, being unintegrated into society or not having friends (Kolstad, Gjesvik 2014). Various researchers have also highlighted that the clear division between physical and mental illness found in the West, is not so obvious in non-Western cultures (e.g., White, Marsella 2012: 17). Cultural conceptions of mental illness or mental health refer to "*common sense* knowledge which is used to interpret social and medical experience, and which plays an important role in shaping both professional and *everyday* views of mental disorder" (White, Marsella 2012: 3).

The social distribution of mental illnesses – research to date

In the case of mental illnesses, as with all other illnesses, we can speak of their social distribution, understood as their unequal prevalence in society and, moreover, their different symptomatology and perception. The phenomenon of the social distribution of health can be considered both within one society and at a cross-cultural level. What may be considered a symptom of illness in one culture may not necessarily be defined as such in another. Loss of appetite is an example of this. Among people in the upper social class in the United States, 75% of people recognise loss of appetite as a symptom of illness, in the middle – 50%, and in the lower social class only 20% (Kobierzycki 2011: 158). Emilia Jaroszewska, on the other hand, notes that in non-Western cultures "depression is more often reduced to psychosomatic symptoms such as fatigue, anorexia and decreased libido", while schizophrenia in developing countries has a much milder course (Jaroszewska 2013: 74).

Researchers and scholars have been demonstrating for years that non-Western societies construct concepts of mental illnesses quite differently from Western ones. According to Adebayo Olabisi Odejide et al., Yorubas in Nigeria indicate the following symptoms of disorders that would be diagnosed as depression in Western medicine: "crawling, heat, peppery sensations, numbness, and vague aches and pains all over the body" (Odejide et al. 1989: 711). The Gandas of central Uganda, on the other hand, distinguish a number of types of mental illnesses, which, according to Vikram Patel, overlap to some extent with those distinguished by Western researchers (Patel 1995). Theodore T. Bartholomew studied popular conceptions about mental illnesses among members of the Ovambo tribe in Namibia. When asked about the symptoms of mental illnesses, his interviewees mentioned: inappropriate behaviour, aggression of people with mental disorders towards others, insulting other people, hearing non-existent sounds and seeing non-existent people, running quickly from place to place, thinking too much, talking all day or saying things that do not make sense, isolating oneself, talking to oneself, abusing alcohol, looking for food in rubbish bins (Bartholomew 2017: 428). Many other researchers have described how mental illnesses are experienced in non-Western societies and how much this experiencing is culturally-relativised (e.g., Patel et al. 1995; Opare-Henaku, Utsey 2017; Ventevogel et al. 2013).

Culture-bound syndromes and cultural idioms of distress

The social distribution of mental health can manifest itself not only in the different course of illnesses depending on culture, but even in the occurrence of certain illnesses exclusively in particular societies (e.g., Jakubik 2003; Krzyżowski 2002; Yap 1962). Such mental illnesses are most often referred to as "culture-bound syndromes" (Jakubik 2003: 139). According to Yap's definition, culture-bound syndromes have unique symptoms that are determined by cultural factors (Yap 1962). Wen-Shing Tseng characterises culture-bound syndromes as follows: "mental conditions or psychiatric syndromes whose occurrence or manifestation are closely related to cultural factors and which thus warrant understanding and management from a cultural perspective" (Tseng 2006: 554). Among such conditions, *koro* and *susto* are often mentioned (Krzyżowski 2002: 55).

Culture-bound syndromes are included in the DSM-IV (Diagnostic and Statistical Manual of Mental Disorders) wherein they are characterised as follows: "The term culture-bound syndrome denotes recurrent, locality-specific patterns of aberrant behaviour and troubling experience that may or may not be linked to a particular DSM-IV diagnostic category" (American Psychiatric Association 2000: 898). However, in the DSM-5, culture-bound syndromes have been withdrawn and replaced by: *cultural syndrome*, i.e., "a cluster or group of co-occurring, relatively invariant symptoms found in a specific cultural group, community, or context" (DSM-5: 14); *cultural idiom of distress* – "a linguistic term, phrase, or way of talking about suffering among individuals of a cultural group (e.g., similar ethnicity and religion) referring to shared concepts of pathology and ways of expressing, communicating, or naming essential features of distress" (American Psychiatric Association 2013: 14); and *cultural explanation or perceived cause*, which the DSM-5 contributors define as: "a label, attribution, or feature of an explanatory model that provides a culturally conceived etiology or cause for symptoms, illness, or distress" (American Psychiatric Association 2013: 14). Importantly, the authors emphasise that all illnesses included in the DSM-5 have a cultural component, and even conditions such as depression or schizophrenia can be experienced differently depending on the culture.

In fact, from the moment Yap presented the concept of culture-bound syndromes, it was questioned. The arguments of critics have focused on the fact that it is impossible to attribute a syndrome to a particular culture and that the incidence of some diseases is not as culturally limited as the concept assumes (Isaac 2013: 357; Ellenberger 2020: 143). Tseng notes that international disease classifications were created in the Anglo-Saxon system and based on the experience of diseases by Western societies. Any conditions that ran differently were seen as "peculiar" or "exotic" (Tseng 2006: 556). In addition, the prevalence of some diseases that were judged to be culturally relativised is extended by globalisation and the influence of the media. Anorexia is a case in point (Kaiser, Weaver 2019: 590). The process of globalisation also makes the boundaries between different cultures blur, so that it becomes increasingly difficult to attribute a particular condition to a particular culture (Ventriglio et al. 2016: 4). Reporting on the debate, Janusz Krzyżowski writes that representatives of critical voices believe that it is not always possible to speak of a specific, relativised syndrome of a disease – sometimes only single symptoms occur and certain symptoms may present in many different cultures, just not in those in the Western world (Krzyżowski 2002: 56). Furthermore, as Tseng points out, sometimes behaviours that should not be classified in this way at all, such as *latah*, are considered as diseases (Tseng 2006: 559). It should also be noted that, from a diagnostic point of view, it is crucial to distinguish between culturally relative symptoms and the illnesses as a whole, that are limited by their incidence to a particular culture (Tseng 2006: 566). In the debate on the relativity of illnesses, there are also claims that what to date have been called culture-bound syndromes by some are actually just culturally relativised symptoms of universal illnesses (Ellenberger 2020: 144).

Ngamuk as a culture-bound syndrome?

To illustrate the phenomenon of the social distribution of mental health in Indonesia, I use the example of Javanese *ngamuk*. *Ngamuk* is a syndrome similar to *amok*, found in the people of Java. According to Andrzej Jakubik, *amok* is "a short-lasting state of acute excitement, constriction of consciousness, physical aggression (up to and including homicide), usually ending in sleep or stupor with amnesia of the disturbed period" (Jakubik 2003: 143). *Amok* can be triggered by a state of extreme embarrassment (Tanra, Roosdy 2017: 187). According to Jilek and Jilek-Aall, this state can also occur in people who do not suffer from mental problems, when the level of emotion is sufficiently high – then sudden and unfounded attacks of aggression occur (Jilek, Jilek-Aall 2001: 234). Martin Manuel Saint distinguishes between two types of this disorder: *beramok*, which involves experiencing a loss and is preceded by a period of depressive mood, and *amok*, which involves more of a state of rage, preceded by a desire for revenge or retribution for an insult. *Beramok* has thus been associated with depressive or mood disorders, while *amok* has been associated with psychosis, personality disorders or delusions (Saint 1999: 67).

According to the DSM-IV classification, *amok* is a culture-bound syndrome. However, this categorisation is disputed by other researchers, firstly because it has been shown that it is not specific to Java – similar symptoms can also be found in countries of other cultural backgrounds (Saint 1999: 66; Jilek, Jilek-Aall 2001: 235), secondly, because some researchers consider it to be a set of symptoms, a symptom of an illness, rather than an illness in itself. According to Martin, *amok* should therefore no longer be classified as a culture-bound syndrome, because the only thing that is different about it is how it manifests itself (just as all other mental illnesses manifest differently) (Saint 1999: 67). Similarly, Ellenberger believes that disease symptoms similar to *amok* can be found in many different societies and over many centuries (Ellenberger 2020: 143). Moreover, *amok* was not always described as a condition associated with a mental health illness. It was initially associated with the behaviour of exceptionally bold men (Murphy 1972: 32). It was not until the Dutch colonised Indonesia that *amok* was recognised – by the Dutch – as an illness. They considered it a form of insanity caused by the opium they imported into Java. Descriptions by British colonisers in the early 19th century indicate that *amok* was considered a form of mental illness (Murphy 1972: 32).

Ngamuk, like *amok*, is associated with aggressive behaviour, but is described somewhat differently. According to Krzyżowski, *ngamuk* "is characterised by fears of mental illness and is often associated with a previously strong repression of emotions in the patient, sometimes preceded by conflict with the environment" (Krzyżowski 2002: 72). Kevin Browne believes that *ngamuk* is a way of manifesting an ailment rather than an illness. According to him, it is an idiom used to describe the vague categories of aggressive, threatening behaviour and mental illness. It is thus a set of emotional and cultural concerns and practices (Browne 2021: 148). It is also a way of framing incomprehensible, aggressive behaviour in terms of a familiar cultural form of mental illness (Browne 2021: 154). A similar view is shared by Manuel Saint Martin, who believes that *amok* is simply a description of aggressive behaviour that is a symptom of depression, psychotic illnesses or a severe personality disorder (Martin 1999: 67). Research by Good and Subandi shows that Javanese use the word *mengamuk* – "to run amok" – to describe outbursts of anger and violence (Good, Subandi 2003: 186). According to Browne in Yogyakarta, the word *ngamuk* refers to a wide range of behaviours that are associated with danger – in particular loud, threatening or aggressive behaviour. The term is used both within and outside professional circles (Browne 2021: 151). *Ngamuk* was cited by Javanese as a symptom that prompted families to bring their loved ones to psychiatric hospitals (Browne 2021: 153), and was also characterised as the most common symptom of mental illness (Browne 2021: 157).

Methodology

The results presented here are part of a study on cultural conceptions of mental illness in Java that I conducted for my Master's thesis at the Department of Sociology, University of Warsaw. I posed three research questions: 1) what are the causes, 2) symptoms and 3) reactions to mental illness according to the inhabitants of Java. The results presented here only concern the part relating to the perception of symptoms of mental illness.

I conducted 31 individual in-depth, semi-structured interviews between October 2019 and March 2020. Ultimately, I included 30 out of 31 interviews in the analysis (Table 1).

Table 1. A brief overview of the interviewees

Interviewee identification	**Group**	**Gender**	**Faith**	**Description**
Z1	a representative of western medicine	Male	Islam	doctor of psychology
Z2	a representative of western medicine	Female	Islam	psychologist from a private practice
Z3	a representative of western medicine	Female	Islam	puskesmas psychologist
Z4	a representative of western medicine	Female	Islam	hospital psychologist
Z5	a representative of western medicine	Female	Islam	hospital psychiatrist
Z6	a representative of western medicine	Female	Christianity	social worker
Z7	a representative of western medicine	Female	Islam	social worker
T1	traditional healer	Male	Islam	ustad
T2	traditional healer	Female	Islam	ustad
T3	traditional healer	Male	kayewen	Javanese healer
T4	traditional healer	Male	kayewen	dukun
T5	traditional healer	Male	Islam	ustad
T6	traditional healer	Male	Islam	priest
S1	student	Male	Christianity	
S2	student	Male	Christianity	
S3	student	Female	Christianity	
S4	student	Female	Christianity	
S5	student	Female	Christianity	

S6	student	Female	Christianity	
Interviewee identification	**Group**	**Gender**	**Faith**	**Description**
S7	student	Female	Christianity	
S8	student	Male	Christianity	
S9	student	Female	Islam	
S10	student	Male	Islam	
S11	student	Male	Islam	
S12	student	Male	Islam	
S13	student	Male	Islam	
S14	student	Male	Islam	
S15	student	Male	Islam	
S16	student	Male	Islam	
S17	student	Female	Islam	

Source: own study.

Importantly, none of these individuals suffered from a mental illness. Therefore, the results are primarily concerned with the perception and identification of symptoms of mental illness, rather than the actual presence of mental illness.

I selected the sample based on my own knowledge of the study population and the aims of the research, opting for purposive sampling (Babbie 2004: 204). I felt that it would be important to include three social categories of interviewees to deepen our knowledge of the cultural definition of mental illness in Java: professionals associated with Western medicine such as psychologists or psychiatrists, traditional healers, and students. I conducted the study in a grounded theory approach. I entered the field without pre-conceptualising ideas or theories. When conducting the interviews, I used emic terms – those used by my interviewees. I constructed the dispositions for the interviews gradually, based on the information I collected.

I conducted the interviews in Indonesian and English languages. The vast majority of interviews with Western medicine practitioners and traditional healers were conducted in Indonesian (including one in Javanese), while I conducted all interviews with students in English. Apart from one conducted in Jakarta and one online, all interviews were conducted in Yogyakarta or close to the city.

I performed the main part of the analysis in Maxqda. The unit of analysis was usually a single sentence or a few-sentence statement. I coded the answers only, without the questions, unless including a question in the coding was necessary to understand the statement. Codes were created on the basis of emic categories rather than external categories imposed by myself (Hammersley, Atkinson 2000: 60).

Ultimately, most codes took an “in-vivo” form – they were words used by the interviewees themselves (Miles, Huberman 2000: 64). I looked for regularities and patterns in the responses, focusing less on individual interviews and more on connecting the material as a whole. I also made use of other tools offered by the Maxqda programme to conduct the analysis, such as the document portrait, the interactive citation matrix, the code matrix viewer, and the code dependency viewer. These were ancillary tools that allowed me to better understand the coded material. The interviewees’ statements quoted in the text are selected to reflect, as much as possible, the thoughts that most people expressed. It also shows the clearest and most intriguing quotes.

The study dealt with the sensitive issue of mental health and its social perception. It was also for this reason that I decided not to carry out the study on a group of people with mental illnesses who could be described as vulnerable. Instead, I felt that talking to non-mentally ill people could yield valuable findings, especially as this group of people has not been widely studied to date in terms of cultural conceptions of mental illness. Participants were responsive to all questions, despite the difficult topic, although at times the embarrassment of the topic could be perceived. When respondents talked about *pasung* – the practice of incarcerating mentally ill people – they tended to lower their voices and emphasised that they were ashamed that this practice was used in their country. Overall, however, the interviews proceeded in a very good atmosphere.

All participants in the study gave verbal, informed consent to participate in the study, to record the interviews and to use the results in the thesis and for subsequent research work. All participants were also assured of the confidentiality of the information provided.

Cultural features of Java and Yogyakarta

Yogyakarta is one of three special regions (Dareah Istimewa) in Indonesia. It is one of two sultanates in Indonesia (the other being Surakarta), but is the only centre where the Sultan still exercises real power – in Surakarta he has a purely representative function. The Yogyakarta region has a population of over 3 million people (the city alone has around 630,000) (Good et al. 2019). The city is considered a unique place. People believe that Kraton – the Sultan’s palace – is the mystical centre of Indonesia and the centre of Javanese culture (Woodwark 2011: 13). It is situated halfway between two other important sites – the Merapi volcano and Parangritis Beach (Subandi et al. 2021). Yogyakarta is a city of many identities. It is known as a city of culture, tourism and students (Subandi et al. 2021: 4). It is considered one of the most important centres of “authentic” Javanese culture. It is also a centre for arts such as batik, a technique for dyeing fabric, and *wayang*, a puppet theatre. It has important tourist sites, such as Kraton, Taman Sari, and the temples of Borobudur and Prambanan. It is the second most-visited destination in Indonesia, the most-visited being Bali. Thousands of students from different parts of Indonesia and abroad come to Yogyakarta (Subandi et al. 2021: 4–5).

Yogyakarta is also specific because of the relationship between culture and religion and between Indonesian nationalism and Yogyakarta nationalism (Woodwark 2011: 3). Few people believe that Yogyakarta should be independent, but many think of Yogyakarta as a nation within a nation. For many Yogyakarta residents, democracy means the right to be ruled by the Sultan (Woodwark 2011: 8). The people of Yogyakarta speak the local language, Javanese, on a daily basis. However, few people can write and read in the Javanese alphabet (which is different from the Latin alphabet) – most people use it only for oral communication.

The overwhelming majority of Yogyakarta's population adhere to Islam, but as in other parts of the country, religion also becomes fused with local beliefs. 86% of the population is Muslim, 10% Christian and the rest form small Hindu and Buddhist communities (Good et al. 2019). However, local beliefs are still practised (although their adherents are most often formally Muslim), with the *Kayewen* religion at the forefront (Woodwark 2011: 81). The Javanese world is one filled with spirits and supernatural powers (Good et al. 2019).

The Javanese have a unique approach to emotions and interpersonal relationships compared to the rest of Indonesia. "In Java social relations are structured in terms of concepts of hierarchy, obligation and mutual assistance. The social as well as mystical ideal is the 'union of servant and lord' and a free flow of aid among equals (*gotong royong*)" (Woodwark 2011: 85). For Javanese, family is central to their lives. This is reflected in the proverb "even if there is no food, being together is the most important thing" – "mangan ora mangan waton kumpul". Even today, with many young Javanese leaving for work or education, family remains extremely important – Javanese try as much as possible to maintain emotional closeness with their family members (Subandi 2011: 333). According to researchers in Java, the boundary between self, family and community is often blurred. Parents remain involved in their adult children's lives, particularly in their marriage (Subandi 2011: 341). The Javanese family also teaches the children not to show intense emotions and to minimise conflict within the family (Subandi 2011: 334). Consequently, any loss of control over one's own behaviour is seen as a symptom of emotional disturbance and problems (Subandi 2011: 337). Javanese try to maintain peaceful relationships (or at least the appearance of such) to avoid conflict. Experiencing frustration, stress or showing feelings of being shocked can disrupt peace of mind (Subandi et al. 2021). Mothers argue that the child should have calm thoughts at all times and that parents should protect the child from emotional and psychological shock (Subandi et al. 2021: 10).

In Javanese culture, a sense of shame is also important for interpersonal relationships (Subandi, Good 2018). It is felt at both the individual and collective level. The sense of shame is important for proper functioning in society. Feeling shame, for example, is necessary for the maintenance of hierarchy, which is extremely important in Java (Collins, Bahar 2000). Children learn emotional control by recognising shame and controlling it. This process is called *ngerti isisn* – knowing shame. Shame is seen as a necessary cultural aspect. Feeling shame is a necessary part of being normal, healthy, moral and mature. It is linked to behavioural control (Subandi, Good 2018; Collins, Bahar 2000). According to Glen Pettigrove and Nigel Parsons, shame is also an important part of experiencing *amok*. Based on their research, they believe that the experience of shame can be a factor in experiencing *amok*. This is especially true for men, as it is accepted in Indonesian culture that the response to men experiencing shame is to behave aggressively (Pettigrove, Parsons 2012).

Symptoms of mental illness in Indonesia – a review of the literature

The symptoms of mental illness as perceived by Indonesians are strongly linked to cultural factors. In the aforementioned studies by Byron Good and M.A. Subandi, one of the symptoms of mental illness described by their interviewees was the sufferer's obsession with religion, or the feeling that certain things like clothes, food and even neighbours are *haram* – unclean, forbidden (Good, Subandi 2003: 186). As Good and Subandi note, in Java, symptoms such as feeling like having an unclean body, being sinful, letting god down or losing his grace are common symptoms of depression (Good, Subandi 2003: 187). Another symptom reported by the sufferer was that in psychotic states he perceives his mother as an enemy (Good, Subandi 2003: 188). In another study conducted by Subandi, his interviewee, who is a mentally ill person, when describing the symptoms of his illness mentioned: lack of control over his own behaviour, being aggressive, feeling tense, being nervous, and having somatic sensations such as a burning sensation in the heart or sweating profusely, as well as visual and auditory hallucinations and thoughts of being followed. The interviewee also made a suicide attempt (Subandi 2015: 600). Good et al. also mention symptoms related to experiencing supernatural forces (Good et al. 2019: 514).

Another cultural symptom of mental illness, in the Javanese view, is the loss of a capacity for shame (Subandi, Good 2018: 34). Shame in this context refers primarily to the loss of eating habits and good manners. The appropriate way of eating was a factor that, in the eyes of the Javanese, distinguished the mentally ill from the healthy (Subandi, Good 2018: 35). Harald Broch, on the other hand, indicates that mentally ill people in Indonesia exhibit deviant behaviour (Broch 2001: 278). Broch also lists such symptoms of mental illness as lack of orientation in time and space, inability to function on a daily basis (e.g., by losing the ability to communicate properly), being aggressive, obsession with religion, and lack of manners (Broch 2001). According to Broch, what characterises the thinking about mental illness among the people of Christian Toraja, where he conducted his research, is aggressive behaviour and the inability to adapt to the cultural norms of society – living in a different world. Other salient characteristics of a mentally ill person include: talking to oneself, shouting, getting angry easily, undressing in public, complaining about the quality of food, and severe and prolonged sleep difficulties (Broch 2001: 297). Andi Tanra and Ireine Roosdy note differences in the symptoms of schizophrenia between patients from the UK and those from Indonesia. Indonesian patients showed mainly hyperactivity, while fewer symptoms related to delusions, persecutions, visual hallucinations or depressive states could be observed in them (Tanra, Roosdy 2017: 190).

Results of own research

Although none of my interviewees used the word *ngamuk* to describe the symptoms of mental illnesses, they extremely often talked about aggressive behaviour as a symptom of mental illnesses – i.e., the main symptom and actually the determinant of *ngamuk*. As my study was conducted in the grounded theory strand, I did not inquire about the prevalence of *ngamuk* when none of the interviewees raised this topic. However, it is possible that because most of the interviews were conducted in English, the interviewees did not want to use the word. It is also possible that they assumed that, as a person from another country, I would not understand the term. However, it is, of course, also possible that the word *ngamuk* has fallen out of use, but that symptoms associated with it are still being reported. This would be indicated by the fact that, after the interview stage was over, I asked some of my interviewees about the word – they indicated that it simply meant anger, but in no way linked it to mental illness.

Other symptoms of illnesses mentioned included: behaviours inconsistent with good habits, difficulties in controlling behaviour and emotions, difficulties in maintaining contact with other people, and psychotic and somatic symptoms. I do not consider the symptoms of individual mental illnesses but, like my interviewees, generalise them. Although some interviewees, especially Western medics, mentioned various mental illnesses, when asked about their symptoms, they were able to point to generalisations. Two interviewees did not mention any symptoms of mental illness. Therefore, this part of the analysis refers to 28 rather than 30 interviews.

Displays of aggressive behaviour by people with mental illnesses were by far the most frequently mentioned symptom of mental illness by my interviewees. According to a doctor of psychology, mentally ill people get angry easily, hurt people and destroy everything (Z1). One psychologist described mentally ill people in a similar way and believes that people with mental illnesses can hurt others (Z2). Another psychologist working in a hospital says: *maybe the person* [with mental illness – AS] *has destructive behaviour, they hurt people, they hurt the environment* (Z4). A psychiatrist, on the other hand, stated the belief that aggressive behaviour is characteristic of psychotic states (Z5). For a community outreach worker, the most difficult patients are those who become enraged (Z7). The woman cites the story of one patient: *he was defending himself inside the house with the weapon, he was prodding every person that was trying to go there* (Z7).

Traditional healers also believe that a mentally ill person is characterised by aggression. One ustad – an Islamic healer – tells the story of a man addicted to drugs who he believed was mentally ill.

> *So the case is the addictive person when he did, like, hurting things to other people because he wants to get the drugs but he cannot so he is, like, reflecting to others. In this case the husband is beating the wife because the wife is trying to stop of using the drugs. So he used to do beat the wife for, like, almost one hour* (T2).

Another case of a husband beating his wife is told by a traditional Javanese healer. His patient was shouting at his wife, hurting her. He behaved this way because of the action of the *jinn* – an evil spirit, in Islamic belief – because an evil spirit makes people very emotional (T3). It is the *jinn*, according to the healer, that forces people to be evil (T3). Mentally ill people not only shout at and beat others but also throw things at other people (T4). In addition, "lunatics", according to another traditional healer, are angry and do not remember what they have done – once the aggressive behaviour has stopped they *do not remember anything* (T5).

The view of aggressive behaviour as a symptom of mental illness is also shared by students. One of them says that there are different types of mental illness, among them there is one in which people attack others (S1). The aggressive behaviour of people with mental illness can, according to one student, be very intense, up to the point of committing murder. When asked for an example of a mentally ill person, she cites a story from the media in which a 15-year-old girl killed a five-year-old girl by *pushing her head under the water until she is dead* (S4). Furthermore, the girl responsible for the murder said that she was happy with what she had done (S4). The same student emphasises that because of the aggression of mentally ill people, Indonesians are afraid of them and are not eager to help such people (S4). This is not the only case where my interviewees told of a murder committed by a mentally ill person – one student said *she wrote and then she did it. She killed one girl* (S12). Another student talking about mentally ill people said: *Because it* [mental illness – AS] *is very dangerous, like you don't know what is happening in their mind and they can commit suicide or be violent for themselves or for someone else, for, yeah* (S6). For another interviewee, a mentally ill person is one who does *not-normal things*. An example of such an activity is carrying a knife everywhere with them and scaring people with it (S7). According to one interviewee, people with disorders hit everything and make trouble for their neighbours. In addition, they bully children. She calls mentally ill people criminals (S9). Another interviewee says: *maybe it is sometimes dangerous for me if they become aggressive. Because sometimes it is uncontrolled, so maybe they will do something like aggressive action or become wild, or something like that. And that is dangerous for me* (S15). Also another student was afraid as a child of a certain "madman" who *is standing in the middle of the road and shouting really loud and sometimes trying to catch us* (S11). Students emphasise that mentally ill people are capable of hurting others (S16, S17). There is also a more emphatic voice: *some of crazy people always hurting somebody* (S13).

Aggressive behaviour as a symptom of mental illness is mentioned by representatives of all the social categories I analysed. I did not notice any differences in the frequency with which this aspect was indicated either between people from different social categories or between followers of different religions. There were, however, differences in identifying the causes of aggressive behaviour. Western medical practitioners linked it to illness, most often to a psychotic state. Traditional healers, on the other hand, indicated that the cause was the presence of a *jinn*. Meanwhile, students very often made the following distinction: *orang dengan ganguan jiwa* – a person with a mental illness (literally a person with a soul disorder) versus *orang gila* – a madman, a lunatic. Aggression was more often linked to *orang gila* behaviour than *orang dengan ganguan jiwa*.

The terms used for the mentally ill were a differentiating element for my interviewees. Western medical practitioners always used the term *orang dengan ganguan jiwa*, only when asked about *orang gila*, they said that most Indonesians still use this term. Traditional healers, on the other hand, overwhelmingly referred to mentally ill people as *orang gila*. Students varied in this aspect, with some using one and some using the other of these terms. Some, as I pointed out, made a distinction between *orang gila* and *orang dengan ganguan jiwa*.

Conclusions

Although none of my interviewees used the word *ngamuk* when talking about symptoms of mental illness, I believe that thinking about such disorders is close to what characterises the disorder. When I asked several of my interviewees after the interviews if they knew what *ngamuk* meant, they said it was simply being very angry, but they did not link it to a medical condition. In contrast, what they said about symptoms of mental illness fit the definition of *ngamuk* as a state of aggressive, threatening behaviour (Browne 2021; Saint 1999). Based on what my interviewees said, *ngamuk* could therefore be a way of manifesting mental illness rather than an illness in itself.

In my opinion, the fact that aggression was mentioned by far the most frequently as a symptom of mental illness is not without significance. This fact, however, does not necessarily indicate a relativistic perception of such disorders. Indeed, it appears that in many cultures, a mentally ill person is seen as dangerous and unable to control themselves (Todor 2013). What seems instead relatable are the various factors that accompany aggression, which in my opinion can be linked to *ngamuk* symptoms. Some interviewees (e.g., Z7) spoke not only of aggression, but even of *rampage patients*. This would therefore indicate exceptionally strong bouts of aggression that fit the definitions of *ngamuk* that I have cited. Aggressive behaviour has also sometimes been linked to the action of supernatural forces, most notably that of the *jinn* – an evil spirit, as understood in Islam. This is also an element that points to the relativism of the views expressed. The response that could most prove the occurrence of *ngamuk*-related syndromes in Java is the words of one traditional healer, who speaks of people with mental illnesses forgetting their violent acts (T5). Jakubik (2003: 143) argues that it is the "amnesia of the illness period" that is characteristic of *amok*, and which is akin to *ngamuk*. Similarly, the example of a homicide committed by a person whom one student (S4) assessed as mentally ill would indicate that the syndromes of these disorders are perceived similarly to the symptoms of *ngamuk* and *amok*. In contrast, a different perception of aggression would be indicated by interviewee S1's statement that aggression is characteristic of one disorder (not all) – one in which individuals harm others. This would indicate the existence, in his view, of a different illness entity, of which aggression would be a determinant.

The dominant role of aggression in talking about symptoms of mental illness can, in my view, be linked to the ethos of controlling one's own behaviour and emotions in Java (Subandi 2011: 337). In this light, it is possible that the hypothesis advanced by Pettigrove and Parsons (2012) and Tanra and Roosdy (2017) that *amok* is a response to shaming is correct. I feel that the Javanese culture, which heavily proscribes the showing of emotion, may mean that at some point these emotions have to resurface and this happens in the form of aggression. As this was a study of perceptions of the symptoms of mental illnesses and not the illnesses themselves, strictly speaking, cultural norms seem to play a dominant role. I conclude that interviewees indicated symptoms that are most closely associated with behaviours that break the norms defined by Javanese culture, including aggression. My findings show that perceptions of illnesses can be as culturally relativised as the illnesses themselves. I postulate that when dealing with illnesses (both mental and physical), the cultural aspect should be taken into account, regardless of the researchers' field of study.

In the light of my research, it is impossible to prove the existence of *ngamuk*. Instead, I believe that my results certainly prove that illnesses are culturally relativised, and in particular the perception of them is relativised. Thus, it shows that they are socially distributed across cultures. Research by other authors shows that mental illness is perceived differently in Western cultures than in non-Western ones. The research I have already mentioned (Kolstald, Gjesvik 2014) proved that behaviours that were identified as mental illness in the West were not perceived in this way in Chinese culture. Giosan, Glovski and Hasam (2001) conducted a study in which participants from Brazil, the United States and Romania were asked to rate which of the listed behaviours indicated the presence of mental illness. The behaviours and symptoms included those listed in the DSM-IV, as well as conditions that in Western culture can be associated more with behaviour that breaks social norms or is regarded as deviant behaviour. The difference became most apparent between Americans and Brazilians. The former were much more likely to point to symptoms included in the DSM-IV as symptoms of mental illness, while the latter pointed mainly to deviant and norm-breaking behaviours (that in Western cultures are not considered symptoms of mental illness per se).

While it is true that also in Western cultures mental illness is sometimes associated with aggressive behaviour, this association is, in my opinion, much rarer than in Indonesia. Moreover, not all illnesses are perceived in this way. The example of Angermeyer and Matshinger's (2003) research on the social perception of schizophrenia and depression in the United States seems to be evidence of this. Aggression was much more frequently linked to schizophrenia than to depression. Aggression was associated with mental illness by 35.7% of respondents who identified it with schizophrenia and 20.7% of the people who identified it with depression. In my opinion, based on the qualitative research I conducted, if an analogous quantitative survey was conducted in Indonesia, these percentages would be much higher.

It would certainly be valuable to explore differences in perceptions of mental illness between Polish and Indonesian cultures. A study constructed in a manner analogous to the one I conducted in Indonesia, done on Polish grounds, could confirm my hypothesis about the unusual importance of aggression in the commentary on mental illness by the people of Java. It would also be valuable to explore differences in social perception of illness within Indonesia itself. This is because it is an extremely diverse country with many distinct cultures. This would be particularly valuable for research on *ngamuk*, which other researchers have argued is confined to Javanese culture.

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Dorota Kowalska-Papke[1]

Becoming a Retiree in the Polish People's Republic and Now: A Comparative Reconstruction of the Transition Experience Using the Example of Applying the Fritze Schütze Method of Narrative Analysis to Four Memoirs

> *Perhaps we should trust fragments, as it is fragments that create constellations capable of describing more, and in a more complex way, multi-dimensionally. Our stories could refer to one another in an infinite way, and their central characters could enter into relationships with each other.*
>
> Nobel Lecture by Olga Tokarczuk
> 2018 Nobel Prize in Literature laureate
> [translated by Jennifer Croft and Antonia Lloyd-Jones]

Introduction

Previous research shows that ending one's professional career and retiring is a turning point in the life of a working person, who at that point relinquishes one of their key roles and faces the task of constructing their new identity (Bullock, Garland and Coupar 2019; Krzyżowski et al. 2014; Lam et al. 2018; Staręga-Piasek and Synak 1990). They become a retiree and give their own meanings to this role. If one's work constituted an autotelic value, the pensioner may be pained by its loss (Tryfan 1990) and other losses connected to it (e.g., networks related to the work

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environment, professional status). The disorganisation of one's routine and the loss of clarity regarding one's social role and status can be similarly unpleasant. The process of finding and solidifying the meaning of a new identity can be termed the process of *becoming* (Strauss 2012) a retiree, which likely takes some time. Regardless of the specific age and physical well-being, this process is often negatively associated with ageing (Kowalska 2015; Krzyżowski et al. 2014). This is because the individual is aware of the advancing degradation of the body, the increasing likelihood of disease and multimorbidity, and the noticeable changes in cognitive functioning (Celidoni, Bianco and Weber 2017; Olszewski 2003; Pasowicz 2013).

With the end of working life, the experience of personal time changes – both on the biographical (it lengthens and shortens), and the everyday scale – a different rhythm and pace, different fixed points and points of reference. Professional affairs, which until now occupied most of one's time and organised the daily schedule, lose relevance. As far as the future is concerned, the prospect of a limited amount of time left to live may be felt acutely. At the point of retirement, this prospect becomes more real: tangible and conscious. In this context, the types of an individual's aims may change to more short-term plans, ones that are less forward-looking and growth-oriented, often of a consumerist and hedonistic nature. In the immediate view, the cessation of work usually means disrupting and changing the daily routine but it can also be seen as an incredible freeing up of time, allowing for more "time to yourself", i.e., an increase in the amount of free time that the individual can use more or less as desired (van den Bogaard, Henkens and Kalmijn 2016; Bonk and Retowski 2013; Henkens et al. 2018). Responses can be very positive – seeing the situation as liberating, or negative – fear of emptiness and some kind of escape from freedom[2]. The temporary unconstrained use of time becomes limited by new obligations, dependencies on others, social norms prohibiting or inhibiting activities, institutional expectations, and finally financial and/or health conditions. Individuals often feel obligated to abandon their own plans and perform their prescribed social roles; primarily the roles of caregivers of those less independent, e.g., the roles of grandparents (Czekanowski, Brosz and Załęcki 2012; Gulin 2019; Rada Monitoringu Społecznego 2015; Synak 1987).

The unique individual human experience depends on many factors, both internal – personal, and external – cultural. The individual biographical narrative, due to the importance of the processes and circumstances outlined above, is a socially shared experience that contains common phases and process structures. Social, political, and economic conditions limit or, on the contrary, widen the range of possibilities available to an individual at this stage of life.

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[2] In the sense used by Erich Fromm in *Escape from Freedom* (Fromm 2011).

Contemporary Poland and the Poland of almost half a century ago represent two different landscapes. The Polish People's Republic was a formally independent state, but according to the provisions of the Yalta Conference it lay within the Soviet sphere of influence. It was an authoritarian state ruled by the Polish Communist Party. The economy was centrally planned. There was no private property. All areas of social life were controlled. All artistic work was subject to censorship. Publications, including competition memoirs, promoted a "new type of man" and glorified labour, which constituted the highest value (Fedorowicz et al. 2011; Kosiński 2003; Palska 1997). During the 1960s, '70s, and '80s, opposition movements intensified due to the lack of prospects, unmet social aspirations, and an oppressive political system, which resulted in some limited liberalisation and – as a result – led to a change in the political system (Fedorowicz et al. 2011; Kersten 1996). In the Polish People's Republic, contrary to government propaganda, access to professional careers and social policy benefits was unequal. Privileged groups included functionaries of the power apparatus, civil servants, and skilled workers in the industrial production sector. In contrast, rural residents, unskilled workers, and recipients of welfare benefits, especially retirees, were among the poorest citizens (Polakowski and Szelewa 2015; Tarkowska 2002). In socialist Poland, social life was subject to strict norms that defined the individual's place in society, or at least limited their choices, which consequently inhibited the individual's reflexive approach to their individual independence. Fritze Schütze explained that the citizens of the socialist state did not undertake "reflective biographical work in the course of their lives" (2012: 275), because the implemented strategy of the state was to "(…) administer work by allocating jobs and apprenticeships to citizens without giving them the opportunity to consider for themselves what kind of profession would resonate best with their unique biographical identity" (2012: 275).

The Poland of the 2020s is a democratic country that has undergone systemic, economic and cultural transformation. It has shifted its geopolitical orientation westwards – becoming a member of the European Union and NATO. Poland is a member of a number of European (e.g., Council of Europe, OSCE, Three Seas Initiative) and global (e.g. UN, WTO, OECD) international organisations. There was an economic transition, which for some people was a period of gaining a high financial status, prestige, and a period of fulfilling their aspirations; for others, it was a difficult period of instability and of difficulties in finding their way in society. In the Third Polish Republic, the social policies implemented follow the activity theory and include measures to foster active ageing. This approach reinforces the inclusion within European structures as well as global trends in this field and demographic changes. The policy currently in force is the *Social Policy for Older People 2030: Safety – Participation – Solidarity*, adopted in 2018, whose name states the focus of action and indicates the most important needs of the ageing population. The fundamental focus is to create a safe, non-exclusionary, inclusive society that does not discriminate on the basis of age.

The individual in modern society, unlike in communist Poland, is constantly faced with many choices. Social position depends almost exclusively on material status. This is because members of modern societies are under pressure to continually consume more and more new goods, while they throw away the old ones because they are reaching their "expiry date". Human identities are subject to permanent change. (Bauman 2007: 5).

In this article, I will contrast the experiences of those who left the workforce and retired in these two very different time periods. I was interested in the commonalities in the experience of retirement; how independent is it of the social environment, the economic conditions, and of the political system? What identity transformations do individuals experience? I will attempt to find the essence of this phenomenon, which is described by individuals living and working in different historical, cultural, political, and economic conditions.

Theoretical and methodological framework

Theoretical perspective

For the analysis, I used the process structures developed by Fritz Schütze (2012) and specifically designed for the analysis of autobiographical narrative interviews. Spoken accounts, such as narrative interviews or free-form interviews, provide more information than do written texts, which is related to the communicative compulsions to which the narrator is subjected when spontaneously telling their story. The narrator tries to convey a coherent and comprehensible story to the interviewer, which results, among other things, in a compulsion to close the frame. This means that each time the author departs from the main plot, they try to return to it. In this way, they make their story coherent, clear and intelligible to the listener and encourage them to listen and follow it attentively. It also happens that the storyteller feels "obliged" to recount also those events from their life that they originally did not want to show to the world. This is particularly true of events and behaviours of which they are ashamed or which are inconsistent with the image they are currently constructing for themselves. In addition, a careful analysis of the interview transcript also makes it possible to notice discontinuities in the story, which may be indicative of episodes that the narrator left out because they did not want to reveal them, so-called "veiling". These mechanisms do not operate in the case of written texts, which are subject to many revisions before they are "released into the world". However, they are sometimes the only – and precious – account of times gone by. However, despite these potential losses in written as opposed to spoken material, diaries or memoirs constitute valuable empirical material in which the author, embedded in the social framework around them, describes their experiences, embedding them in this framework.

In the course of an individual's life, there are periods in which individuals act intentionally, meaning that they take action to realise their plans and intentions. This analytical process structure has been referred to by Schütze as the realisation of a **"biographical action scheme"** (Kaźmierska and Waniek 2020; Posłuszny and Kubicki 2019; Prawda 1989; Schütze 2012). Schütze noted that the course of an individual's life cannot be described only from the point of view of the "social action" paradigm (Schütze 1981: 88–89 after: Prawda 1989: 83). People do not always act intentionally. In the course of life, there are periods when the individual acts according to socially imposed norms, abandoning their individual goals and adopting **"institutional expectation patterns"** as determinants of their own thinking and action.

Schütze made a clear distinction between active "acting" and more passive "experiencing". At certain stages of life, when an individual starts to come under strong pressure from external factors and they are unable to act intentionally under their influence, their life is increasingly taken up by "experiencing". For this situation, Schütze uses the concept of **"trajectory"** and links it to the experience of suffering, borrowing Anselm Strauss's (2016) concept of the trajectory of illness and developing it. Schütze's concept of the trajectory of suffering not only shows the workings of independent external factors that the individual is unable to counteract and that lead to suffering and crisis in their life, but also draws attention to the individual's previous actions that led them into a winding spiral of suffering. Despite the individual's efforts-actions aimed at taking control of their own life, the actions taken lead to the opposite results, which may even result in a complete loss of control over one's life. Trajectory is the process of "experiencing" dominated by external factors and, at the same time, a sequential process in which identity is transformed and previous values lose their relevance. It is a process that leads to suffering. Trajectory describes difficult life events; both individual ones affecting the person directly, such as loss of a job, severe or long-term illness, disability, as well as collective experiences such as wars, epidemics, emigration, and political transformation (Schütze 1997, 2012, 2014; Waniek 2020). Schütze also distinguished a trajectory with an ascending line, which is usually omitted from consideration because it very rarely occurs. In this trajectory, the individual gains new opportunities.

The next process is **"metamorphosis"**. Metamorphosis is process of creative inner changes in an individual's life that creates new opportunities for the individual to act, develop, and see themselves differently.

The course of cessation of professional career in terms of Schütze's process structures

Ending one's professional life in terms of the process structures defined by Schütze follows several patterns depending on the course of the retirement process, i.e., 1) the career path in professional life and especially that part of it before retirement (e.g., the conditions for the [non-] decision to end professional life, the freedom of this decision, the termination ceremony, the farewell), 2) the transition, and 3) the experience of life in retirement. I introduced this classification following the work of Arnold van Gennep (1960), who first categorised the various rituals of transition processes in 1908. His contemporaries praised his work (Starr 1910), which organised the various processes of transition – serving multiple needs (birth, engagement, marriage, funeral, among others), requiring dissimilar rituals and occurring in varying time frames – into three sequential parts: 1) a "preliminal" phase with rituals of separation, 2) a liminal phase with rituals of transition, and a final third 3) incorporation phase – an "postliminal" phase with rituals of inclusion.

Professional work can be the realisation of one's own biographical plan or it can be the realisation of institutional expectations. Immediately after leaving education, an individual may decide consciously or not quite consciously to follow the expectations of significant others or cultural patterns. They abandon their career plan because they do not want to resist or because they decide that their intentions are not the best. They succumb to cultural norms voluntarily, even unknowingly, or under social pressure. Sometimes they follow their peers because they do not have a clear vision for their future.

However, it is not always the case that the individual who pursues their biographical action scheme feels fulfilled and successful and experiences satisfaction and prestige. This happens when the individual is troubled by organisational restrictions in the work environment, encounters an unfavourable atmosphere, has difficulties with interpersonal interactions, does not achieve success, experiences health-related limitations, etc. On the other hand, a person following and fulfilling institutional expectations, even though it is not their own plan, may like their job and be successful in it.

During working life, transitions occur between following one's own biographical plan and following institutional expectation patterns, and vice versa. The breakdown of a biographical plan can occur at any time, for example when a person loses their job, the labour market collapses and they are unable to find another job compatible with their qualifications, or health problems arise.

Retirement can be a severe shock to the individual, fostering a trajectory of suffering and feelings of uselessness, emptiness and rejection. It introduces a state of isolation and loneliness. The efforts made to take control of one's life lead to the start of a retired life, which can follow different patterns:

- the retiree who succumbs to the stereotype of being useless, old, sick, passive, complaining, lonely;
- the retiree who begins to fulfil social expectations according to the prevailing institutional norms. Most often, in the case of women, the retiree performs family roles: taking care of grandchildren, dependents. A common occupation of the elderly who are not working is caring for a garden plot. However, these activities, in many cases, constitute the implementation of a biographical plan. Classification depends on the meaning people attach to these activities;
- the retiree who regains control of their life and finds rewarding activities among the activities that older people commonly engage in and begins to realise their biographical plan;
- the retiree experiencing a metamorphosis finds new challenges, new areas of activity. They undertake the realisation of a new and rewarding biographical plan.

Another pattern of retirement is the conscious withdrawal from one's career to pursue one's plans. Such individuals look forward to the end of their work and have defined in great detail or only in outline the activities they will be engaged in when retired. When they leave their jobs, they are energised, satisfied and enjoying the new chapter of their lives. For them, retirement is an anticipated stage which they do not associate with negative stereotypes or restrictive activity patterns for older people. They begin to implement their biographical action scheme. In this case, the patterns for retirement vary depending on career history:

- if professional work has been a disliked and tiresome fulfilment of institutional expectations, retirement has the character of a metamorphosis. The individual finally breaks free of the institutional ties that constrain them, and begins a new phase of life that they have defined for themselves;
- if professional work was the realisation of a biographical plan and was rewarding, but despite this, the individual has decided to end it, it means that a new plan of activity in retirement is more appealing to them than the continuation of their previous activities. The individual gives this phase of life a high importance, which determines the decision to leave professional work. They begin to implement a new biographical plan or, in some cases, the change may have the character of a metamorphosis.

The reasons for leaving the workforce might not derive from a desire to fulfil one's plans in retirement, but could be related to deteriorating health or the need to meet family expectations. The retired individual fulfils the tasks expected of them or, in the case of pressure or difficulties in adapting to a new situation, gradually loses control over their life and enters a trajectory of suffering.

In summary, using the sequential division of transition formulated by van Gennep and Schütze's process structures, I distinguish twelve theoretical patterns of retiring (there may also be more or fewer) (Table 1).

Table 1. Theoretical patterns of retiring

	Phase (rites of separation)	**Phase (rites of transition)**	**Phase (rites of incorporation)**
I	biographical[1]/norm[2]	biographical[1]/norm[2]	biographical[1]
II	biographical[1]/norm[2]	biographical[1]/norm[2]	metamorphosis
III	biographical[1]/norm[2]	biographical[1]/norm[2]	trajectory
IV	biographical[1]/norm[2]	biographical[1]/norm[2]	norm[2]
V	biographical[1]/norm[2]	trajectory	biographical
VI	biographical[1]/norm[2]	trajectory	metamorphosis
VII	biographical[1]/norm[2]	trajectory	trajectory
VIII	biographical[1]/norm[2]	trajectory	norm
IX	trajectory	trajectory/biographical[1]/norm[2]	biographical
X	trajectory	trajectory/biographical[1]/norm[2]	metamorphosis
XI	trajectory	trajectory/biographical[1]/norm[2]	trajectory
XII	trajectory	trajectory/biographical[1]/norm[2]	norm

[1] biographical action scheme
[2] institutional expectation patterns

Source: own study.

In the author's pattern presented, in the pre-liminal phase, the realisation of the biographical action plan or institutional expectation patterns do not form separate patterns, as their distinction depends on the meaning given by the individual. Furthermore, a person's well-being, their life satisfaction, does not depend entirely on whether the individual follows their own plan or follows social expectations. In contrast, the pre-retirement period, which is associated with suffering, with loss of control over life, with passive experiencing, creates different patterns. Being in the trajectory of suffering involves biographical work, efforts to take back control of one's life and regain an active role, to move out of a state of passive experiencing.

In some cases, the transition phase lasts a long time, especially when it becomes an increasing feeling of suffering due to the loss of values that gave meaning to life. This makes incorporation into the retired population more difficult, but at the same time does not limit the possibility of constructing a positive self-definition – of entering into the process of metamorphosis, or of building and implementing a satisfying biographical action scheme, or of realising oneself by following socially expected patterns of retired behaviour.

Research methodology

To carry out the analysis, I used diaries submitted to the *First Year in Retirement* competition announced in 1978 and memoirs written in 2018 by non-working retirees whose subject was describing the experience of leaving the workforce and retiring.

The use of diaries as empirical material has a long history beginning with the epoch-making work of Wilhelm I. Thomas and Florian Znaniecki *The Polish Peasant in Europe and America*. Memoirs and diaries are a valuable source of information and are a special kind of record of memories and accompanying self-reflection. They present the expression of the author's thoughts on past events (Posłuszny and Kubicki 2019). It is not a flaw that the author may be tempted to deviate from reality, veering away from depicting the truth, in order to make the recorded story a more interesting one, one that will attract and engage the attention of the potential reader and that will give more satisfaction to the narrator themselves. For sociological analysis, it is important to delve into both the narrator's subjective world and to unravel the meaning of the communicative situation in which they find themselves, and to look for the social mechanisms that influence them and those that regulate individual attitudes and actions. Stories, memoirs, and diaries provide material that would not otherwise be available (Kubera 2015; Rancew-Sikora and Skowronek 2015: 10–11).

The path to identifying universal and specific characteristics and patterns of the process of retirement and leaving professional work in contemporary Poland and during the communist period was to analyse autobiographies that dealt with one of the phases in the course of life, i.e., the phase in which the end of professional work and the transition to retirement occurred. The narratives provided a basis for examining this process to identify biographical process structures and explanations of their operation in specific cases. Focusing on the type of experiences lived – such as realising one's own biographical plans or following institutional patterns of expectations, going through a trajectory (suffering) – made it possible to see similarities and differences between the experience of becoming a retiree during the communist period and now. The adopted research strategy is based on the assumption that autobiographical processes both reflect and create social reality (Berger and Luckmann 2010).

Studying specific cases allows one to go beyond their individual reality. On the other hand, changing circumstances can alter experience, can reveal a generational character that is unique to people born in similar periods of time, under specific socio-institutional conditions, who finish their working lives. The analysis of the stories of leaving work and retiring will therefore show, on the one hand, the biographical line and, on the other hand, the political, economic, and social conditions in which the individual's life is immersed. "The analysis of an individual's colloquial 'autobiographical productions' thus implies an attempt to get closer to reality through the recognition of 'biographically reconstructed' social phenomena" (Prawda 1989: 82). Furthermore, the authors provide information about the sequence of events as well as share the meanings they assign to them, the accrual of their knowledge and experience.

The diaries which constitute the empirical material, were submitted to a competition announced by the Związkowa Oficyna Wydawnicza publishing house and the weekly magazine "Kultura" in 1978. Twelve selected memoirs were published in a book with the same name as the competition, *First Year in Retirement* (Łapiński 1981). The organisers did not provide information on what criteria were used to select the memoirs or how many memoirs were submitted for the competition. The narratives contained in the collection, like all works published during the communist period, were subject to censorship by the Main Office of Control of Press, Publications and Shows (the editorial footer shows the censor's approval: Zam. 978/80. L-14). It is not possible to say whether and how much the memoirs were altered, as the censored material was not marked in the text. The memoirs in the collection were written by four women and eight men, ranging in age from 58 to 74, mostly in their sixties. All but one had been collecting a pension for no more than five years (some were still working). The man who had previously worked as a miner had been retired for 19 years. The publication included the recollections of a nurse, a doctor, a pharmacist, a salesman, an economist, a miner, an engineer, a manager, and a director. For the analysis, I selected the memoirs of a woman doctor and a man who spent most of his working life as a director.

The memoirs from 2018 were written mainly at my request by people attending classes run by the University of the Third Age. In general, all the diarists, both those of today and those from the communist period, had a higher education. The diarists from the communist period generally belonged to a privileged class – they had higher salaries and better access to social benefits (Polakowski and Szelewa 2015). The contemporary memoirs are short descriptions, spanning a few pages, about the time of leaving the workforce and becoming a retiree. The memoirs from the communist period are longer, averaging several dozen pages.

I based my analysis on four autobiographies, two from each time period studied. I applied a strategy of maximum contrast for the liminal phase in the retirement process. On the one hand, I chose a challenging transition phase, which I define as a difficult pain-related transition that has the character of a trajectory and, on the other hand, I chose diaries describing a benign and/or expected end of career. In addition, a component of the selection of memoirs was the third phase of the process – the phase of incorporation into a new role – that of a retiree. The diarists selected for analysis, as a result of experiencing the process of transition and incorporation into a new social group, positively constructed their new identity as retirees. They have taken control of their lives in retirement. The selected memoirs illustrate the theoretical patterns: I (possibly II, which applies when the individual gives their time in retirement the meaning of metamorphosis) and V (possibly VI – ibid.). For obvious reasons (censorship), a diary whose author would describe work as an experience of growing suffering could not be included in a publication from the communist period. This explains the impossibility of comparing the process of leaving work of people who gave the experience of work the meaning of trajectory.

The starting point for my interpretive research was a single case study. I have assumed that each story represents a unique whole. It shows the individual dimension of events and experiences and therefore lends itself to separate interpretation. After analysing each story, identifying the process structures described in them, their consequences, and the combination of the sequence in which they occurred, the next stage was to look at what emerged as commonalities and what emerged as unique in the life stories told and analysed.

In presenting portraits of individuals, I have retained the names the writers used in their diaries.

Portraits of diarists

Doctor Zofia, 1978

The catastrophe of retiring. From the loss of professional identity to the surrender to institutional expectation patterns

From realising a biographical plan, through a trajectory of suffering, to taking on unfulfilling family responsibilities

Zofia was a doctor-internist by profession. At the time of writing her end-of-career story, she was in her second year of retirement. She had worked in her last job for 22 years, in the health service for just under 25 years. She did not want to retire.

She began her story with the moment she retired. For her, it was a "shock" (Frąckowiak 1981: 56). She experienced the end of her career as "a side-lining, a pathetic epilogue to everything that had gone before" (1981: 57). For the first few months she could not find a place for herself, she could not believe she would not go to work anymore. Her environment – acquaintances and friends – unknowingly contributed to deepening her feelings of suffering. They congratulated her on her retirement, because in their opinion being a non-working retiree was great and she should be happy to start a new phase of her life. They completely failed to understand her sense of emptiness and breaking down. The author bitterly adds information about the lowering of her financial and social status.

The experience of leaving her career was a significant turning point in the author's life, the arrival of which she had no control over. Attempts to extend the working period or take up part-time employment had no effect and have multiplied the helplessness and the sense of injustice she felt. This intensified her suffering. In communist Poland, permission from the Employment Department (Łapiński 1981: 244) was needed to continue working past retirement age and, as the author herself repeatedly emphasised in her diary, she did not enjoy the favour of her superiors as a consequence of her uncompromising nature. A rapid trajectory of suffering began the moment she received the decision to be transferred into retirement. Sequentially occurring external events on the one hand, and a small and dwindling range of possible actions on the other, drastically reduced her scope of control over her life and gradually increased her anguish. The author found herself in a rapidly intensifying spiral of suffering and helplessness. In the narrative, she outlined the palette of emotions she felt as she transitioned into the world of retirement. She felt shame, bitterness and a diminishing of her value and social status: "I was reluctant to admit that I was no longer working, I felt a kind of shame that I was no longer needed, bitterness that I no longer needed to be reckoned with, which is – unfortunately – sometimes felt in interpersonal relations" (1981: 58). The status transition experienced by the author was both clear and significant for her and those around her. In communist Poland, work was elevated to the highest value in a person's life. Shock workers were put on the pedestal of social life; they were the celebrities of the time. They were honoured with state decorations, received valuable awards and were promoted (Fedorowicz et al. 2011). The status of a non-worker was not high. The author was painfully affected by the system of values and the culture of the period in the Polish People's Republic. The completing factor lowering her self-definition was the lowering of her financial status. Retirees in the People's Republic of Poland belonged to an underprivileged social group, and were impoverished (Polakowski and Szelewa 2015; Tarkowska 2002).

Zofia began working on her new identity – that of a retiree. She began biographical work in order to take control of her life. Over time, the author adapted to her new situation. Following institutional norms, she took on the role of grandmother and carer for her grandchildren and domestic help for her adult children. The author disliked this work, which was beyond her physical strength and deprived her of "time for herself" "in peace and quiet" (1981: 61). Zofia rebelled:

> Namely, I would like daily life to be easier, especially for women, so that it does not require so much effort and toil even in trivial matters, which does not result in satisfaction, but brings fatigue and an unwillingness to take care of the home. So that women are not so busy and preoccupied with domestic concerns, which leave a narrow margin for personal interests and activities that give satisfaction (1981: 70–71).

The author drew attention to the disadvantaged position of women after retirement. According to current social norms, women are required to help their children, take over the care of grandchildren or loved ones in need of care (Frąckowiak 1981; Synak 1987). The propaganda of the Polish People's Republic reinforced this norm due to the insufficient availability of institutional care for children and the sick (Polakowski and Szelewa 2015). This reflection is amusingly concluded by the author: "So why not… extend the working time of women who would like to do so, and send them into retirement earlier from… full-time domestic work?".

The author devoted the greatest part of the story to reflections on professional work. She wrote about the heartlessness of the management, about the inadequacies of the health care system. She jotted down her reflections and the resulting suggestions for improving the health care system and the organisation of work in medical facilities. These reflections confirmed that Zofia remained in the world of the health service, even though she had been pushed out of it; she still seemed – in her mind – to be stuck in it.

In summary, the decision to move Zofia into retirement began a rapid trajectory of suffering that escalated over the following few months. The trajectory began after the end of a long career as a doctor-internist, during which the diarist pursued her biographical plan. However, due to adversarial relationships with her superiors, working in her coveted medical profession was not an entirely fulfilling period for her; it was difficult in parts. After retirement, Zofia began to make efforts to adapt to her diminished social status. She tried to build a new identity as a retiree, to find new goals, to start a new biographical plan. Zofia did not have significant resources in the sense of financial, health, and energy resources. In addition, the Polish People's Republic did not offer retirees many opportunities and they were certainly not valued members of society. Zofia undertook a life conforming to institutional norms – acting as a carer for children and taking care of disliked domestic chores. She is bound by social compulsions.

Director Henryk, 1978

Privileged member of socialist society

A change of satisfying biographical schemes from worker to retiree

A different biographical profile of the stage of retirement can be found in the story of the sixty-year-old Henryk. He had worked at a number of jobs in different industries. He was a coachman and coalman, waiter and fitter, resistance soldier, prisoner of war, interpreter at the UN, foreman of tractor drivers, head of the Provincial Department of Culture, inspector of state control bodies and director, successively in two state enterprises and, at the end of his career, manager of a poultry plant. He was compulsorily retired for health reasons before the age of 60. His first heart attack took him out of work as a director. The two years of pensionable service he was missing were spent as a manager. Two more heart attacks took him out of work completely. Henryk was a university graduate (he does not specify the field of study he completed). He was a prisoner in the Bergen-Belsen concentration camp (Rostkowski 1981).

Like the author of the previous story, Henryk was very committed to his professional work. It was a joy for him and gave him great satisfaction. It was the realisation of his biographical action plan. He could not imagine life without work. He wondered: "(…) what will I do 'afterwards' [in retirement]. How will I fill the hours?" (1981: 221). He was going through a pre-retirement phase forced by his health (Atchley 1985), which did not help him find his place in the future. He was concerned that life in retirement, without work, would be difficult, that nothing would fill the space that work occupied. Henryk's last two years at work were not his biographical plan; it was his illness that decided that the most important – according to him – part of his life had ended. Despite the confluence of unwelcome events in his life, the author did not fall into a trajectory of suffering. He tried to find a satisfactory solution for the rest of his life, with which he partly confirmed his self-assessment, presented in the "preamble" to his memoirs, as a mentally and physically resilient man who triumphs in difficult situations.

Henryk did not actually go through the transition phase – the liminal phase, the phase of transformation. By coincidence, just after he had finished his career, a friend asked him to help him improve his English. Henry knew English, German and Italian. He started helping his friend, which turned into a permanent and regular occupation in his retirement. Giving English lessons became an activity he valued, one that brought him "satisfaction and improved self-esteem" (1981: 222) and was a source of pride. His "students" achieved their planned goals, which facilitated their professional and/or personal careers.

He developed a new hobby – collecting pennants and gathering information from magazines and newspapers, which he called creating his own "encyclopaedia of knowledge". Several people benefited from his "encyclopaedia of knowledge". All these activities brought him much satisfaction and appreciation from those around him. He still felt needed and appreciated. The activities he performed brought him satisfaction. A good command of the English language (Henryk travelled abroad and was an interpreter at the United Nations) was a rare skill in socialist Poland, where the borders for "ordinary" citizens were closed, so people who had a need to learn English highly valued Henryk's practical language skills. Similarly, his "encyclopaedia of knowledge" was a valuable source of information. Books were not widely available during the communist period. They were expensive. Encyclopaedic publications required sign-ups, there were long wait times and not everyone who wanted them received them. Henryk's hobby was helpful and useful, as the author writes, to many people. Henryk felt his usefulness and prestige. He gave meaning to his activities.

The only activity he engaged in that he did not take much pleasure in was tending to a garden plot. He cultivated it together with his wife and for this reason this activity continued. Cultivating garden plots was a common hobby for retirees during the communist period (and still is today).

Retirement, in Henryk's case, was not a sudden change. After the first stay in the hospital, he did not work for some time. However, he did not experience the period of inactivity he had feared, as he was offered the opportunity to write his life story. The book was published. When he returned to work, he was aware that he would only work for two more years at most. The time away and the change to a less demanding and less stressful position was helpful in smoothing the transition to retirement. Although the activities he engaged in during retirement were mostly incidental and not planned by him, the satisfaction felt, the fulfilment of aspirations, and the desire to continue them show that Henryk was following his biographical plan in retirement. In his case, becoming a retiree was neither a trajectory of suffering nor a metamorphosis.

In his memoirs, Henryk shared his reflections on the final matters: death (of which he was not afraid), the values that give life meaning, the future of the world. His most important values were "a steadfast and kind attitude towards people and the environment" (1981: 226), which came from his upbringing, and an appreciation of other people's work and toil. Furthermore, he formed a conclusion about his life: "… the first, most important element was precisely the fact that I was given the opportunity to live in a period when I could fight for my homeland and lay the foundations of the New Poland. (…) And then? The last thirty years were also a kind of struggle. With abuses, with heartlessness, waste, crime…" (1981: 228). This quote confirms Henryk's immersion in the narrative of the socialist state. The author uses the ideological language of the communist period. In this way, his memoirs were one of the many elements of the creation of a "new man" in socialist Poland (Kosiński 2003; Palska 1997).

The author found fulfilment in professional employment. After finishing his work life, he was also realising his biographical plan. Thanks to his entrenchment in the structures of socialist Poland, he was a privileged member of society, as evidenced by the successive promotions and high state awards he received, including the Order of Polonia Restituta. His life career developed without hindrance. He recalled the acknowledgements and gifts received from the Soviet Government with pride. In retirement, he felt needed, useful and appreciated. Unlike that of Zofia, Henryk's retirement was neither painfully nor clearly felt. His social status remained high. His identity was undergoing a gentle and slow change to that of a retiree who feels he is a useful and valuable member of the socialist state. Although the activities he took up in retirement were incidental and had not been planned by him, Henryk appreciated their value, derived satisfaction from them and was happy to continue and develop them.

The retirement phase was necessitated by health conditions and was not voluntary. Despite this, Henryk's memoirs do not contain descriptions of a loss of control over his own life, passive waiting or a lack of order. The author presents himself as a person who copes well with life's difficulties. His reasoning is consistent with the reported events of his life. However, it should be noted that Henry belonged to a privileged group of members of the socialist society.

Manager Malwina, 2018

Painful loss of professional employment leading to metamorphosis

The realisation of a biographical plan, a trajectory of suffering, a foreshadowing of metamorphosis

After graduating from university, Malwina worked in various jobs. During the last years before her retirement, she worked as a director. Her retirement was compulsory – she was over the legal retirement age and her managerial contract ended and was not renewed. At the time of writing her story she had been retired for 2 years.

She was involved in professional work that she enjoyed and that gave her satisfaction and joy. Before retiring, Malwina had many interests and activities outside of work, but she did not devote much time to them as many hours were taken up by her professional work. She enjoyed travelling, especially to faraway exotic countries. She organised some of her trips herself. She practised sports at a nearby sports club and went skiing in the mountains every year. She enjoyed walks, Nordic walking with her peers, and socialising. For the author, the period of professional employment described in her memoirs was the realisation of a biographical plan. It satisfied her aspirations and provided a sense of usefulness. The author experienced personal growth. She worked together with people with whom she carried out projects and achieved the set goals. Malwina motivated her subordinates, helped them develop and climb the career ladder. Their successes filled her with satisfaction and pride. Malwina did not describe the entire course of her professional life. She only focused on describing her work just before retirement. The language of these reflections is rich in positive descriptors, which may indicate that Malwina's professional career constituted a metamorphosis for her. The thinness of the empirical material does not make it possible to clearly identify this process structure, as there are no references to previous life stages. However, the period of professional employment before retirement was, for Malwina, definitely either a satisfying realisation of her biographical plan or a metamorphosis.

Malwina was not preparing to end her career. She wanted to work. For her, the moment of retirement came too soon and unexpectedly. She did not go through the separation phase; she did not experience the rituals of the "before" phase. Malwina did not plan for what her place in society would be after her career ended. She had not "worked through" the pre-liminal phase, which may have been one of the reasons for her suffering in the transition phase (Atchley 1985).

The liminal phase was a trajectory of suffering for Malwina. When she ended her career, she "felt angry, discouraged" (2018: 1). She felt apathy, a lack of motivation to do anything. She ceased to enjoy the activities which she had passionately pursued in her spare time while still working professionally. She lost interest in travelling. Social gatherings bored her, conversations seemed superficial to her. She was not interested in discussions about health, about recipes, about family events. She did not find peace in reading books or watching films (2018: 1). Malwina could not find ways out of the abyss of "the feeling emptiness" (2018: 1), where "I felt sad, I felt useless" (2018: 1). In her memoirs, she gives further information about what intensified her suffering. "The children were grown up and independent. What else is there to do in the world. Live to die?" (2018: 1). She continues: "Everything seemed superfluous, unnecessary, pointless" (2018: 1). A devastating sense of inertia possessed her. She could not find herself – that energetic manager – in the lost Malwina. She felt separated from herself. She undertook biographical work, which is "a reflective examination of inner states and overall personal identity" (Schütze 2012: 148). She did not give up. She looked for alternative modes of interpreting and understanding her own evolving identity. She searched for solutions, directions and potentials for development (Schütze 2012: 148), which she did not find at the beginning of the transition phase. Her experience of the lack of exit routes compounded the spiral of suffering. The author experienced a loss of control over her life to an increasing degree. She became increasingly immersed in passive experiencing, losing active responses. As a result of the biographical work she undertook, Malwina realised that in recent times, work had given meaning to her life, which was incompatible with her ironclad conviction that children came first. Secondly, retirement made her aware of the approaching end of her life. She felt healthy and had no health-related limitations, but this thought strongly inhibited her consideration of the future and limited the actions she could take. Malwina entered a trajectory of suffering when she left employment. The trajectory of despair developed in spite of the activities she undertook, such as socialising, books, cinema, and recreational activities which were meant to counteract the feeling of emptiness. The experience of the first days and months after retirement was similar to that described by Zofia, the author of the biography from 40 years ago. Malwina did not mention financial difficulties or a decrease in income. Finances were likely not a problem for her (she held senior, generally well-paid positions). Like Zofia, in retirement, she did not feel needed. The words "living to die" (2018: 1) are a poignant indication of this. She did not see activities in which she could engage, in which she would feel fulfilled, in which she could positively construct her individual and social identity[3]. The context provided by the information that her children had grown up is indicative of her traditional perception of her role as a non-working woman. The feeling of not being needed that she expressed at the beginning of her memoirs, in contrast to the previous period of her life full of activity, involvement, sense of satisfaction and pride, was definitely an expression of a sense of deprivation of her value, a sense of decline and deterioration. It can be hypothesised that, despite, the absence of any account of interactions during which she was considered less important or valuable than she was when she was working, her psyche reflects a sense of inferiority. This may have been related to the unflattering stereotypes of the elderly pervading the public space: ailing, useless, ill-adapted to technological change, taking up the space of the young (Levy et al. 2014; Makita et al. 2019; Potent-Ambroziewicz 2013). Malwina did not directly mention the pejorative patterns of perceptions of the elderly – the generation to which she began to belong due to her retirement – but she included them indirectly by pointing to the lack of satisfying roles set by society for the non-working. Perhaps, however, the essence of the source of the perceived emptiness was the feeling of losing something important in her life – the loss of her professional

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[3] Identity – it is a set of ideas, judgements and beliefs of a social actor (individual and/or social) about themselves. It usually refers to the sphere of self-definition. Individual (personal) identity is understood as a system of knowledge about oneself; social identity is associated with a sense of group membership.

identity – with which Malwina identified. The activities she undertook could not replace her professional work. Loss was the main determinant of her suffering.

Malwina began to work on developing her identity. Unlike the protagonist of the first story, she did not intend to follow institutional norms, but to seek her own path and find her own satisfying biographical plan. The new phase of her life, for which Malwina's memoirs only outlined the framework, could become a metamorphosis. She expressed the will and conviction that she would find sufficiently satisfying activities on which she could build her new identity. In working on herself, Malwina directed her efforts to turning trajectories into intentional activity that would put in motion an exciting biographical plan. She noted that she had previously dismissed the implementation of her plans because she felt that the projects she wanted to tackle required too much work or too much time relative to the time she potentially had left. In her biographical work, she recognised these as misconceptions about herself. She resolved to reject the notion that she was too old to take on new activities or projects. She decided it was important not to assume in advance that she would not be able to tackle them, or to calculate that they were pointless, or to take into account possible negative assessments and opinions from those around her.

Business owner Anita, 2018

Planned retirement results in a satisfying role of a retired woman

The realisation of a biographical plan and the metamorphosis of retirement

The second analysed story from the 2018 collection was written by Anita, the owner of a real estate agency. Retirement was her decision. At the time of writing the memoirs, Anita had been receiving her pension for three and a half years. She ended her gainful employment later: she had been a working retiree for a year and a half, meaning that at the time of writing her story she had not been working for two years.

Anita began her recollections by describing a celebration she had organised to mark her 60th birthday. It was then that she first began to reflect on the end of her work at the company. In accordance with the law in force at the time, eight months remained until Anita could apply for a pension. The author decided to end her career as soon as she had acquired her pension rights. She would then begin the life of a retiree, which she associated primarily with freeing up time "for herself". Anita had clear plans, which she intended to start implementing. She planned to devote her free time to her favourite activities, including reading books, socialising, and going to exhibitions and the theatre. She began the work of separating herself from her previous activities, her daily routine. She was the owner of a one-person business. For her, the decision to leave her job was tantamount to a decision to let go of the company. She considered selling it, handing it over to a relative, or liquidating the company.

Anita's work required a significant time commitment from her. She enjoyed her work, was committed to it, and took pride in it. It seems that it was only in the final period that the intensity of the work began to bother the author. Anita described it in the following words:

> At eight in the morning, I am already sitting in front of the computer. The whole day is calls, making appointments, doing documentation of newly accepted properties, running between government offices. And when evening comes, instead of sitting quietly at home, I have to hit the road again for apartment showings (2018: 1).

She had a growing conviction that work was not what should take up all of her time, and a belief that she needed to find time for other activities. Approaching retirement age brought thoughts about the impending finish line of life and reflections on activities that might bring her a sense of fullness of life. Her words indicate this: "How many more years do I have to stand under these stairwells this way? And life is running out…". Anita noticed that work was not developing her and that she did not have time for the activities she enjoyed. She began to feel the need to return to activities she used to really enjoy, such as reading books, and other horizon-expanding activities that would enliven the daily monotony. The author began biographical work on developing her personal identity. She noticed that engaging in hours of paid work was the wrong life path. She built and connected her identity to her professional work, to her status as a business owner. She began to construct a plan "in order to realise and crown this development" (Schütze 2012: 149). She made the decision to stop working; she decided that she had had enough of this, as she put it, "grind" (2018: 1).

She began the implementation of a new biographical plan for the next phase of her life – her life in retirement. Anita had planned everything, she knew what she would do, what activities she would undertake. She remarked: "It's high time to finally become the mistress of my own time and do what I feel like doing, not what I have to do!" (2018: 1), and further affirmed this need: "I've been dreaming of a day that doesn't end with scheduling client meetings, but with thinking 'What do I feel like doing tomorrow?'" (2018: 2). Retiring was a planned action, taken after much thought. It was the implementation of a plan. It did not have the character of a turning point. Perhaps also because Anita was the owner of a micro-enterprise. The end of her career could not occur in the same way as for some other people – salaried employees or those employed in some other form – i.e., by leaving an organisation which continued to operate. The rituals of separation from professional work, such as, for example, saying goodbye to co-workers and supervisors, taking one's private belongings, and cleaning one's desk and office, did not apply to her. They were different. Anita had to hand over or liquidate her company. This task took her a year and a half.

Initially, Anita wanted to sell the business but, after unsuccessful attempts, she began the process of shutting it down. Simultaneously, during this time, Anita started attending various activities designed for senior citizens. In her memoirs, Anita expressed a positive opinion of the activities for seniors offered by the local government and other organisations. She described it as interesting and extensive. She began to take part in the activities for seniors. She mentions excursions, free gymnastics classes, and attending lectures and workshops at the University of the Third Age. She commented on enrolling at the university: "And it was a hit" (2018: 2). At the university, she not only expanded her knowledge and developed her hobby (photography) but also savoured "meeting many positively eccentric people there, for whom the PESEL is just a string of silly numbers that should not prevent anyone from pursuing their passions and dreams" (2018: 2). Anita described the activities she was able to pursue in her retirement: meetings with friends, concerts, theatre performances, author's evenings, reading books. She added that some of her time is devoted to family. She occasionally looks after her grandchildren. When she was working, she did not have time for family gatherings. In retirement, she meets her grandchildren, including the one who lives in England. Anita describes her time in retirement in superlatives. She described the moment of the complete end of her career, the closure of her business: "It was a happy day. I already knew very specifically what I wanted to do with the time I still had left…" (2018: 3).

Retirement was a kind of metamorphosis for Anita. She began to notice and pursue new activities and activities she had abandoned during her working life. Reading books had always been her passion, but previously, when she was working, she would fall asleep after reading only a few lines. Anita felt satisfaction with her new identity as a person who expands her knowledge, pursues her passions, is energised, acts and builds good relationships with others. She describes new activities which fill her with joy. Thanks to activities offered to seniors and ones she organised herself, Anita has become energetic and dynamic again. She has changed her daily routine. Previously, her job had required many hours of her time at all times of the day. When her career ended, she was able chose the time and activities with which to fill that time herself. She appreciated having time at her disposal and being able to organise it according to her individual needs.

Discussion. Universality and uniqueness of the transition from working to non-working status

Four people, four life stories, four different experiences of the process of leaving the workforce. Although the experiences of these people today and half a century ago are rooted in different political, social, economic conditions, they contain similarities, feature a similar sequence of analytical structures, and in them one can detect analogies in the surrounding external conditions. Both generations experienced profound changes. The lives of the authors of the memoirs from the era of the Polish People's Republic were firmly rooted in the culture and ideology of the period. They lived their childhood in Sanation-era Poland. Some diarists extensively describe the poverty and unemployment that painfully affected them and their families. Their youth was marked by the horror of the Second World War. Then they experienced the change of regime and the necessity to adapt to life in an authoritarian, ideology-saturated system. Contemporary retirees experienced only a fragment of their lives in a socialist state: their childhood and youth, and the older ones also a part of their mature lives. They grew up surrounded by the ideological propaganda of the "new man" (Kosinski 2003; Palska 1997). These two generations lived through massive regime changes: the retirees of the Polish People's Republic – from Sanation Poland to socialist Poland, and the younger ones – from socialist Poland to a democratic state. They were participants in the creation of new regimes, changes in values, which may have induced in them a sense of maladjustment or incoherence, or generally a sense of anomie (Durkheim 2006; Merton 1982).

Commitment to work

A strong commitment to work, including on an emotional level, is a common factor in the life stories of retirees today and those of half a century ago. In communist Poland, these accounts reflected the common narrative in the public space about the supreme value of work for human beings. All the authors of the memoirs liked their professional work; it constituted the main axis of their lives. They all talk about their work using similar descriptors, except that the authors from more than 40 years ago paint their work in more expressive and emotional terms. It had "the greatest value" for them, as Zofia puts it (1981: 57). Each of the four authors realised their biographical plan through their work. Their identities were constructed in relation to work. Essentially, the "before" (preliminal) phase – of the authors of the communist-era memoirs in the framework of Schütze's structures – was the realisation of their biographical action plan. Although they followed the patterns accepted in society for this phase of life – that of a person of working age – they gave work individual meanings. They saw it as the realisation of their life plans.

Degree of choice in the decision to stop working

Retirement can be categorised according to the reasons behind the decision to leave work. It can be, both today and in the Polish People's Republic, a volitional act with a rich spectrum of reasons, or an involuntary act, resulting from a decision by the employer or other objective reasons related or not related to the employee, such as legal or economic requirements. The decision itself depends on both external and internal factors. Internal reasons include the attitude towards work. Some people enjoy their work and most often derive satisfaction from it. They often construct their identity on the basis of professional career. Others see work as an unpleasant necessity, required to earn a living, from which they want to get away as quickly as possible. For many people nowadays, the main reason for giving up further employment is the relationship with co-workers and superiors or other components of the workplace atmosphere. In the Polish People's Republic, older workers, despite an unsatisfactory workplace atmosphere or adversarial relations with superiors, still wanted to work, as Zofia describes in detail in her diary. This difference can be explained by the ideologisation of life in the Polish People's Republic, the lack of activities offered to people of post-working age, or, finally, the stereotype of the old person. A common and important element determining the volitional retirement of contemporary retirees and retirees in the communist period is poor health.

Retirement as loss – memoirs of Zofia and Malwina

For Zofia (the retiree from the contest memoirs) and Malwina (the contemporary retiree), the end of their careers took the form of a violent trajectory of suffering. In their cases, it became apparent that the combination of leaving work and suffering could occur despite having a wide range of interests and despite activities available to seniors (this was the case for Malwina). Work dictated the routines of their days and occupied their thoughts and time, which may explain the reason for the sense of painful loss that initiated the trajectory of suffering. Zofia and Malwina wanted to continue working. Their retirement was forced by external factors to which they had to submit. Their employment was not extended and they did not find others jobs. Even when unfavourable relations with management disrupted the satisfaction of realising their biographical plan, work continued to be a lifelong mission which – Zofia writes about this – as a doctor, was appreciated by patients. For them, the loss of work was associated with a persistent sense of decline and uselessness.

Work is also linked to the loss of the network of contacts that are its natural consequence. Colleagues, supervisors, clients, suppliers, patients, etc. with whom the employee has daily contact suddenly disappear with the end of employment. In some cases, cordial ties with people from work remain, but they are of a different nature. They are no longer a simple daily routine that does not require the individual to put in additional effort.

The specificity of the characterisation of the end-of-work trajectory

The end-of-work trajectory has a peculiar character. It does not build up sequentially but occurs abruptly with the moment of ending one's career. Those affected experience an acute state of anguish. Then, slowly, over time, individuals make efforts to work through their biography, to construct new, satisfying identities. Some experience a metamorphosis or realise their biographical action scheme, others take up roles conforming to social expectation patterns. Sometimes they remain in a trajectory, break down, experience loneliness, and decline in health.

Zofia and Malwina likely did not have the close personal relationships that usually facilitate transitions through difficult periods. They do not mention support from others. Zofia (a retiree of the Polish People's Republic) wrote about the loss of contact with patients who often confided in her, told her about their concerns, and with whom she formed close relationships. Their absence deepened her sense of loss and broadened her awareness of loneliness. Zofia only described her family from the perspective of its demands on the author: from the perspective of duty to the family and working to serve it. This subjective picture of post-work activity, as presented by Zofia, is certainly not appealing. She did not see any positives; she did not enjoy the freeing up of her time. She knew that the rewarding paid work that gave her good social standing would, in retirement, be replaced by unpaid, unappreciated, hard work for her family – and she was correct. Malwina (contemporary retiree) does not describe such reflections, but neither does she find any aspects of retirement that would be appealing. Both authors painfully experience the separation from their careers.

Different dimensions of life expectations in retirement

The process of leaving employment, which represents an objective change in a person's life, is experienced subjectively in different ways. Looking at these varied experiences, one can see that, in some cases, the process is very dramatic – it is a profound negative change experienced as a "catastrophe", while in other cases it is an expected positive change. There is a wide range of feelings in between these two aforementioned boundaries. People are now living longer and being a retiree for a longer time. When they finish employment, they often enjoy good health. This has led to the emergence of a new term: the "third age", which, in contrast to the "fourth age", describes people who are active, who are seeking their place in society and finding their way in life. The population of elderly people has become an interesting target group for many businesses. New branches of the service industry are being developed for them. The term "fourth age" (Giddens 2006) refers to people who are sick and often dependent on the care of another person and/or institution. This is a relatively new phenomenon, partially because the multigenerational family model is disappearing – older people often form separate households which creates demand for institutional care services. The communist period focused on people's professional work, as it was a time of rebuilding industry, agriculture, and housing from the ruins of war. After retiring, people did not feel needed. There were no activities on offer for them (excluding garden plots). This is where one can see a clear difference retirees of the Polish People's Republic felt happy if they could continue their professional work or agitational activities. Meanwhile, today's retirees are primarily focused on activities that will develop them, that will be enjoyable. They mostly plan for consumption-related goals. This is how they understand the meaning of their further life. Bauman's (2007) fluid society is reflected in the considerations and chosen activities of contemporary retirees.

Over the years these memoirs span, social attitudes towards this final stage of a person's life – being a retiree – have changed significantly. Nowadays, many people plan to pursue their dreams precisely during this period. As a result, they want to end their working life as soon as possible and start living the active life of a happy retiree. These beliefs are widely promoted by mass media, social media and companies in industries offering services to non-working customers. In many circles, social attitudes glorify the quick cessation of professional work. An important attraction to retirement is the amount of pension benefits, the level of social security, the prevailing retirement age, the quality of health, and the diversity and availability of activities for retirees. This view of retirement is reflected in the dreams and plans of today's retirees. Tourist trips to near and far corners of the world are often the activity of choice for wealthier retirees; socialising, outdoor activities and watching films, reading books, as well as creative literary and artistic endeavours are popular. Retirees of the the Polish People's Republic period did not have this many opportunities. Retirees then belonged to the poorest strata of society (Polakowski and Szelewa 2015; Tarkowska 2002). For the most part, they lacked financial resources and, moreover, the borders of the socialist state were open only to other countries within the Soviet sphere of influence.

Retirement as a new rewarding stage of life

For the next two authors (Henryk and Anita), the end of working life was not associated with difficult experiences. For both Anita, retiring in the 21st century, and Henryk, ending his working life almost half a century earlier, retirement was a new satisfying stage of life; in the case of Anita – planned and expected; for Henryk – forced, related to health problems. For them, retirement was a time to pursue new activities, continue hobbies, or build interpersonal relationships that they did not have time for during their working lives. Henryk, a well-established director of state-owned enterprises in socialist Poland, did not experience a lowering of social status. He did not feel a sudden change in daily routine. He was helped by his party colleagues (he did not use this term in his story) thanks to whom, immediately after leaving work, he had an interesting occupation. For Henryk, retirement was the next stage in his biographical action plan. The activities changed, their intensity decreased but they still gave him a sense of usefulness. He used his competences and skills in the activities he pursued. Henryk, who had feared a life without work, quickly adapted to his new situation.

Anita, the author of the 21st-century story, took up activities in retirement that developed and enriched her, and began to realise her plans and dreams. She chose from the opportunities that emerged from the surrounding reality. Anita experienced a positive transformation – a metamorphosis. She was full of optimism and enjoyed life and activities that she did not have time for when she was working – reading books, meeting with interesting people, learning photography.

Women

In her diary, Zofia shares her reflections on the different situation of women as opposed to men in the Polish People's Republic. She describes her disagreement with society's normative demands on women and with the lack of opportunities to achieve the goals she aspired to. For her, retirement meant providing unpaid work for her adult children – as a nanny for her grandchildren and a housekeeper for their home. Propaganda of the Polish People's Republic, due to the inadequate care infrastructure, reinforced this pattern of identity of a retired woman (Frąckowiak 1981; Łapiński 1981; Polakowski and Szelewa 2015; Synak 1987). Despite the fact that caregiving and domestic work was physically too difficult for her, Zofia undertook it without argument. For her, accepting socially defined responsibilities was unquestionable and obvious. She did not consider the possibility of resisting them. She unconditionally conformed to social norms, potentially leading her to enter a new trajectory of suffering in the future.

Nearly 50 years later, Anita views her post-employment family responsibilities differently. The role of a grandmother is also – like for Zofia – obvious, but in a completely different scope. She wanted to concentrate on her own needs and her self-development in retirement. And these were the activities she undertook. She limited her assistance to her adult children and prioritised her own plans. In conclusion, the women authors of the stories differ considerably in their acceptance of the responsibilities imposed on them by prevailing institutional norms. Moreover, societal expectations have changed. The social pressure on women, related to the obligation to perform work for adult children, is no longer as strong as it was in the communist era.

Summary

In conclusion, it must be stated that citizens of the Polish People's Republic lived in a state that profoundly restricted their life choices through administrative decisions (cf. Schütze 2012). This also applied to provisions related to retirement. Nowadays, social policies implemented by the state at all administrative levels, in line with EU guidelines, support the active life of older people. Thus, the range of possible activities is broader. The end of one's professional career, i.e., the transition from working to retired status, is immersed in social reality, just as is the rest of life. As the analysis shows, political, economic and social conditions have influenced the perceptions of one's activities in retirement. Today's retirees, if they have adequate resources (including health, energy, and financial resources), design retirement as the fulfilment of their interests and dreams: tourist trips, sports, and social, civic and cultural activities. Retirees of the Polish People's Republic – the authors of the memoirs – were happy as long as they could continue working. They constructed their identity differently. They were heavily influenced by socialist ideology and infatuated with professional work. Objectively speaking, they did not have sufficient resources or opportunities to construct their self-definition in terms other than professional.

The memoirs of those for whom retirement was associated with suffering are surprisingly similar. A sense of emptiness, uselessness, confusion and loneliness, a growing feeling of the loss of control and transition from a state of active to passive feeling is shared by both diarists. The trajectory of suffering affects people regardless of the previously performed professional roles or the degree of activity in professional and private life.

Retirement is a complex, multidimensional process, felt subjectively and individually, although it affects entire age cohorts. It is one of the most important turning points in the course of a person's life. Retirement schemes are independent of the historical situation and the economic and social conditions. For the individual, retiring can constitute a metamorphosis, the realisation of a biographical action scheme or institutional expectation patterns and a trajectory of suffering. Individual ambitions and goals, as well as standards of living, are subject to change. They are shaped both by social reality and by individuals who reciprocally influence their environment. The perspective on the perceptions of this stage of life is generational, unique to people born in a similar period. It depends on the social conditions surrounding the individual but also on their own resources. Retired people want to realise their plans and find new opportunities (biographical action schemes or metamorphoses); they want to be useful to their adult children or fulfil other functions expected of them (institutional expectation patterns or biographical action scheme). In view of contemporary demographic trends which record the continuous growth of the elderly population, the issue of the perception of the role of the retiree in the individual dimension becomes important in the social dimension. The quality of the retirement process, the individual's choices of activity, in particular those that promote health and the continuation of working life, are becoming highly relevant to the health of the economies of individual states.

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