

THE QUALITY OF LIFE OF PEOPLE WITH DISABILITIES DURING THE COVID-19 PANDEMIC

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Abstract: The study analyses the quality of life of people with disabilities during the Covid-19 pandemic based on the data collected from the survey. The logit model, linear model, Chi-squared test and significance test for proportions were used. The study found that during the pandemic the main influence on quality of life of disabled people came from variables that deteriorated the respondents' mental health.

Keywords: disability, quality of life, pandemic, mental health.

1. Introduction

The outbreak of the Covid-19 pandemic has affected the quality of life of nearly everyone, and especially those with special needs, which were not met because of the circumstances and consequent restrictions.

There were different kinds of problems that appeared due to the pandemic. The overworked medical staff and the postponement medical treatments other than emergencies kinds caused deterioration of the health condition of the whole population. Due to the Covid-19 pandemic in 2020, there were almost 12 million fewer medical consultations, particularly in April and May during the lockdown in Poland (NFZ, 2021). A similar decrease was observed in terms of hospitalization. In April and May, a third (15,000) fewer diagnosis and oncological treatment (DiLO) cards were issued (NFZ, 2021). However, there were many other kinds of problems caused by the national restrictions. The economic crisis influenced many people's financial security. Registered unemployment increased in Q1 of 2020 compared to the last quarter of 2019 (5.47 vs 5.1). This growing

tendency was observed throughout 2020 (GUS, 2021). The restrictions in personal contacts also caused many psychological problems due to the deprivation of social needs, which were not fully met by on-line contacts, especially within groups of older persons and children, see e.g. (Glac, 2020; Kocejko, Bakalarczyk, & Kubicki, 2021).

The section of society whose life during the pandemic became particularly difficult comprised people with disabilities. In Poland, according to the National Census of Population and Housing from 2011, nearly 4.7 million (12.2% of the population of Poland) were disabled (GUS, 2011). Apart from the fact that this number decreased compared to 2002, there is still necessary to focus on their special needs. During the pandemic, healthcare, rehabilitation, or even meetings with other disabled people were restricted; additionally, not all facilities were prepared to service disabled people, e.g. by Internet or by phone. The pandemic resulted in more attention paid to the needs of disabled persons, however, this was concentrated more on the ‘silver generation’ – such as “Hours for seniors” in the shops – designed to prevent older persons from infection rather than protecting the disabled. Unfortunately, these problems (which are just a few examples that disabled people needed to cope with) were not highlighted by the media, and in contrast to the problems of the silver generation, were not widely represented in the public sphere. What is more, nearly all the actions undertaken with the intention of helping disabled people were taken by private persons, e.g. influencers, not by authorities or policy makers.

The aim of this paper was to investigate the subjective feelings of people with disabilities with respect to the perceived quality of life during the pandemic, with special attention to factors that were the most felt.

The paper is organized as follows. In the next section, some general considerations of the needs of people with disabilities during pandemics are presented. Section 3 outlines the survey, based on which the results were obtained and discussed in Section 4. The final Section 5 offers some conclusions and summarizes the paper.

2. Literature review

“The COVID-19 pandemic has presented an ongoing challenge especially for those people and children with disabilities as their voices are unheard of in normal times and this unfortunate situation is heightened during this emergency“ (Toquero, 2020).

There are a few main reasons why persons with disabilities are at special risk during the pandemic (Parchomiuk, 2021). First, such persons more often than the general population have an underlying health problem

(e.g. Stevens, Courtney-Long, Gillespie, & Armour, 2014). It is known that comorbidities increase the risk of the severe symptoms of Covid-19. For example, some diseases may give rise to cytokine storm (see e.g. the case study of a patient with fragile-x-syndrome in (Kleiman et al., 2020)). Second, as compared to the general population, a higher percentage of persons with disabilities live in congregate care settings (Landes et al.; 2020; Taylor, 2018). Third, people who rely on assistance with personal care are unable to maintain social distancing (Boyle, Fox, Haverkamp, & Zubler, 2020). Fourth, some may have problems with both communicating the symptoms of illness and obtaining proper information (Boyle et al., 2020; Lake et al., 2021). Fifth, the restricted access to healthcare may be a special problem for those who need constant rehabilitation, without which their health would deteriorate. This access, both in Poland and in other European countries, has been postponed due to the shift of medical resources to intensive care (e.g. Leocani, Diserens, Moccia, & Caltagiorne, 2020). Next, while the pandemic has caused difficulties in the general labour market and many persons have lost their jobs, this influence has been especially negative for the 'protected' workshops (Kołodziejczyk, 2021). Finally, "people with physical disabilities might be at particular risk of emotional distress" (Ciciurkaite, Marquez-Velarde, & Brown, 2021; Steptoe & Di Gessa, 2021).

Although there are strong advocacy groups recommending steps to limit the impact of the pandemic on people with disabilities (cf. Allen, Smith, 2020; Senjam, 2020), the degree of this impact is still unknown due to the lack of data (Bernard et al., 2020).

At the same time, the pandemic situation provides some paradoxical opportunity for creating a new social image of disabled people. We have witnessed in Poland the enhanced social actions for disabled persons (e.g. Avalon Extreme, 2020; Fundacja Neuron+, 2020; PFRON, 2020), although the proper estimation of the overall impact of those actions and the pandemic itself on the perception of the disabled persons still requires time (Ochocka, 2020).

Based on the existing literature pointing out special difficulties that face the disabled during the pandemic, the respondents were asked questions about their quality of life during that time, concerning the following identified areas: health, work and mental health. The main goal was to investigate whether mental factors play a more important role than 'material' factors. The preliminary thesis, based on the interviews with disabled persons in rehabilitation in hospital is that the mental factors are more severe.

3. Materials and methods

A survey containing 24 questions was prepared and made available at some Internet forums for people with disabilities. The respondents were asked about the kind and degree of their disability, including their evaluation of the formal statement of the degree of their disability. Since in Poland, statements of disability are considered to be difficult to obtain and there a minimum of a few formal instances that can grant the certificate of disability, it is not a matter of course that all persons that should be granted this status indeed obtain it and if so, whether the declared degree complies with the perceived degree of disability. Questions about sex, age, place of residence and financial situation were also asked.

The essential part of the survey consisted of three main parts. One part included questions about the subjective perception of the (inner) states of the respondents – how they felt. Namely, they were asked about the change in their subjective quality of life caused by the pandemic, and which main factors, according to their feelings, caused this eventual change. Basing on the general knowledge about the quality of life and its components, the potential factors were selected e.g. loneliness, financial situation, healthcare and rehabilitation, as well as their capability of finding a job with a specific disability. The respondents were also asked to identify three main aspects troubling them during the pandemic, and about their perceived overall quality of life compared to the situation before the pandemic.

The second part consisted in questions about some possible impacts of the pandemic on the respondents lives. They were asked whether they agree, e.g. that they feel lonely or abandoned by society. The difference between this set of questions and the previous part was that the respondents were not asked to estimate the degree of the impact of different factors on their quality of life but just to agree or disagree with a certain set of statements. This allowed to better grasp the extent of some phenomena. In the earlier set of questions, the respondents were to choose only three among the whole set as the most important ones which lowered the quality of their life. However, it could happen that although not being among the strongest three, some factors may still be very strong. The analysis of this second part of the questions allowed to clarify the extent of some negative phenomena among disabled people.

The third part of the questionnaire included questions about the respondents' views on their objective situation in the context of the pandemic. It was expected that such feedback from this very group might provide a clue for activists and those of policymakers who tried to support disabled persons during the pandemic. Thus, the respondents were asked whether they agreed with some statements about the external conditions

compared to the time before the pandemic, e.g. whether the access for medical treatments was more difficult, etc.

A total of 228 respondents filled in the questionnaire, 34% men and 66% women; over 50% of them with a physical disability (50.9%), 18% in its multiple forms, and 13.6% a visual disability. Psychological, intellectual, hearing, neurological and cardiac disabilities numbered below 7%. The age of the respondents varied, most were under 40 years old (64%) which may be due to the form of survey as it could only reach people with Internet access; 69% of the respondents lived in cities, moreover, 35% had higher education.

In regard to the female part of the respondents, the main impact on psychological discomfort came from general uncertainty about the future (57%), while in the second place was concern for relatives (50%). Feeling lonely obtained 20% less than for men, for whom it was the major aspect. It is a common belief that women constitute a more 'social' part of society. Surprisingly, there were men who placed loneliness (50%) at the top of the most influential aspects in that case, followed by general uncertainty about the future (49%) and concern for relatives (42%).

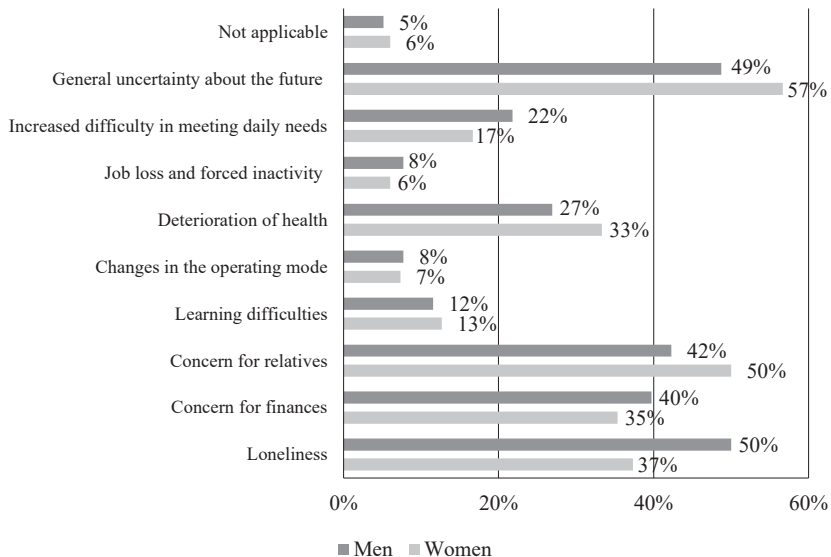


Fig. 1. The main aspects causing psychological discomfort during the pandemic (in %)

Source: own elaboration.

Many different factors may have contributed to the lowering of the quality of life (see Figure 2). Most people agreed that the ability to fulfill social needs greatly decreased, mostly due to the lockdown and

restrictions. In the case of basic needs – over 40% reported the emergence of barriers. Almost 50% of the respondents pointed out decreased access to healthcare and (43%) rehabilitation, while 35% claimed that the pandemic had a negative impact on their mental health, and nearly 40% – on their financial situation; 30% stated that their disability lowered their possibilities of working and (40%) finding a job. They mostly did not report problems with obtaining prescriptions (only 13.5%).

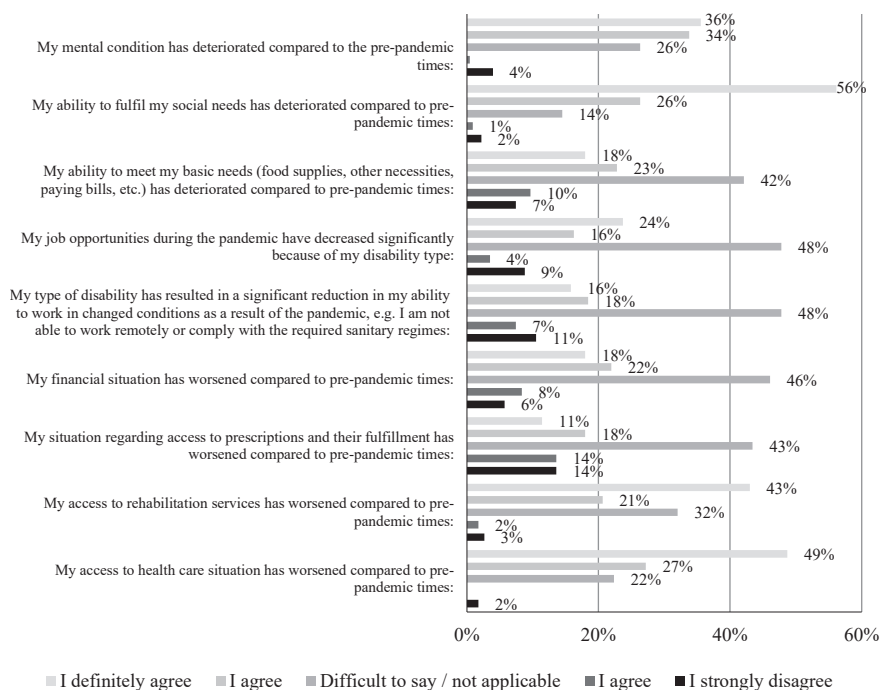


Fig. 2. Share of responses

Source: own elaboration.

In fact 59% of women were afraid of a permanent deterioration of their health due to the pandemic, whilst 44% revealed concerns about their financial situation and increased loneliness (43%). As for men, the most important was the influence of the restrictions on the life of those with a specific disability, which is the reverse of ranking concerning worries about money when compared with women (38%, i.e. 6% more compared to women), see Figure 3.

For deeper analysis, significance tests and logit models were applied.

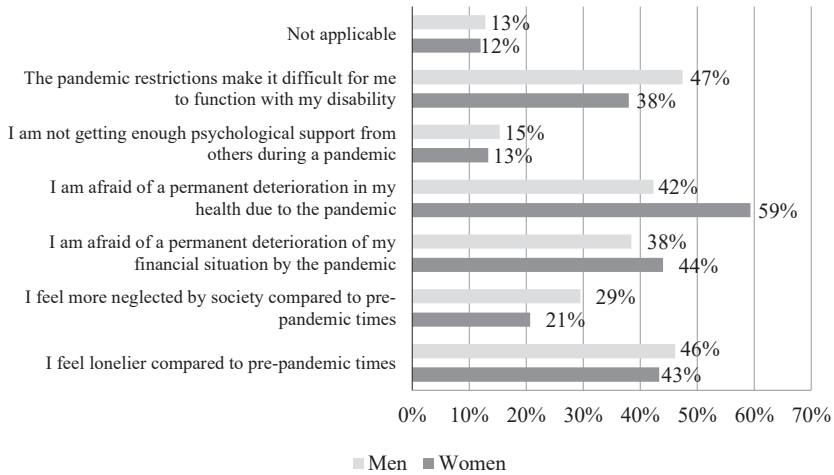


Fig. 3. Share of factors that impacted on the respondents' life during the pandemic (in %)

Source: own elaboration.

As for logit models, the features characterizing persons were sex (F/M), age (in years), education (primary, secondary, etc.), place of residence (coded as 0 for village, 1 for small city, etc.), degree of disability (1, 2 or 3) and financial situation (very bad, bad, moderate, good, very good). Certainly not all the features treated here measured at the interval scale were actually correct (e.g. place of residence), but the number of observations was not large enough to apply a more accurate multinomial approach. Thus, the author is aware that the methodology lacks some precision. As for the dependent variables, if the variable in question was chosen as one of the three main factors – it was coded as 1 if chosen, and as 0 if not. Regarding questions in which the respondents were to estimate the impact on their lives of some set of factors, the answers were grouped “completely agree” and “agree” as 1, and “don’t know”, “do not agree” and “completely do not agree” as 0.

4. Analysis

Since, in general, the deterioration of mental health was reported by most of the respondents, the author was interested in investigating which particular factors were most likely to influence this deterioration. The results of the logit model revealed that all factors, which were significant, had a positive effect. This is not surprising, as all those factors were different kinds of fears. It should be recalled that only people with disabilities were examined.

Table 1. Factors negatively influencing the mental state of the respondents

Factor	Odds ratio
Loneliness	8.60
Health	6.96
Work	4.42
Concern about finances	4.38
Difficulties in meeting needs	4.04
Learning difficulties	3.26

Source: own elaboration.

proper classifications of the model was almost 80%. Not surprisingly, the biggest influence on the condition of mental health resulted from loneliness: the respondents who reported this feeling were almost nine times likely to report the worsening of their mental state compared to those who did not feel lonely. Furthermore, fears about the health and changes in their 'operating mode' increased by almost seven and four and a half times, respectively, the chances of reporting their worsening mental state. There was no doubt that fears about finances influence mental health: it seems that feeling this particular fear increased the chances of a deterioration in mental health by over four times. Finally, difficulties in meeting daily needs and learning difficulties lowered their mental state by about four and over three times, respectively.

As the group of respondents comprised persons with different personal characteristics, e.g. sex, age, education, etc., it was interesting to examine which of these characteristics, if any, made the respondents more susceptible to particular symptoms (emphasizing that the respondents are people with disabilities). First, the differences between the sexes in reporting certain particular problems were investigated, and it was found that there were significant differences (at 0.05 significance level, see Table 2) between sections of disabled men and women who reported loneliness, fears about relatives, worsening of their state of health and the general fears about the

Based on the logit models for the deterioration of mental health, a hierarchy of different factors may be created (Table 1), using the odds ratios for those factors which turned out to be significant. Out of the nine independent binary variables, only three (fears for relatives, forced idleness and fear about future) turned out to be insignificant (at 0.05 significance level), and the percentage of

Table 2. Values of the test statistic and the p-value for significance tests for the equality of percentages for men and women

Parameter	Test statistic	p-value
Loneliness	3.00	0.001
Fears about relatives	2.41	0.008
Deterioration of the state of the health	1.80	0.036
General fears about the future	2.65	0.004

Source: own elaboration.

future. Interestingly, it was men who more often reported the problems with loneliness.

The logit models for several feelings as dependent variables were examined, with personal characteristics as independent variables. In the case of each feeling as a dependent variable, different numbers of independent characteristics turned out to be significant (see below), but in each case the percentage of the correct classifications of the model was about 65%.

The logit model for reporting loneliness revealed that the other significant (at 0.05) factor is the age of the respondents – and the influence of this factor is negative. Psychologists are alarmed about the younger groups in the context of their lack of social interaction – and it seems that for this special group, i.e. disabled persons, this can also be a crucial factor. However, it is also worth noting that women are about 40% less likely to choose loneliness as one of the most important variables.

In the logit model for fears about finances, there are three significant features. People in a better financial situation are less likely (36%) to report that feeling, which is quite an intuitive result. Moreover, groups living in bigger cities report it 25% more often, which can be caused by the generally higher costs of living there. The unexpected outcome was for educational background. It turned out that respondents with higher education are more than 50% more likely to have concerns about their financial situation. It is known, however, that higher educated people have better chances to stay employed during pandemics. However, respondents reported their own feelings, which do not have to be necessarily strictly related to the objective situation. Moreover, the group investigated here is restricted to the disabled, whose main source of income may be social benefits. In that case, difficulties in the labour market do not concern them.

In the logit model for fears about relatives, only age turned out to be significant. According to the odds ratio (1.0186) with an additional year of life the possibility to indicate that feeling increases by almost 2%.

In the model for the worsening of the state of the health, one of the significant factors is age (odds ratio 1.0341), which is understood through the obvious fact that the older person is, the more health problem he/she has in general. Another significant feature is the state of finances (odds ratio 0.6698), probably due to private health care.

Surprisingly, in terms of the model for general fears about the future, having a good financial situation increases the chances to feel these fears (odds ratio 1.575), and that result is significant at 0.05 significance level.

The characteristics of groups reporting these syndromes in the second part of the questionnaire were often also significant and striking. Disabled men significantly more often reported the feeling of being neglected by

society, whereas women were more afraid about their financial situation. The main difference was in the frequency of fears about the permanent deterioration of health (disabled women reported it notably more often). However, men more often complained about difficulties due to the restrictions.

As for opinions of the respondents regarding external conditions during the pandemic, higher education and a better financial situation lowered the possibility to report the general life situation becoming worse, by about 50% and 45%, respectively. Other significant variables had positive effects. Fears about the permanent deterioration of health and concern for finances (the odds ratios respectively 2.3200 and 2.3412) indicate that the possibilities of a negative development of a life situation are in both cases more than two times higher. Loneliness (2.0174), feeling excluded by society (2.0678), and insufficient mental healthcare support (3.5257), significantly increased reporting a general worsening of their life situation by two times (for the two first factors, odds ratios of 2.0174 and 2.0678, respectively) and three times (for the last one, odds ratio of 3.5257). Finally, the study checked whether there was a relation between the type of disability and reporting the deteriorated life situation. The V-Cramer coefficient was equal to 0.190, characterized as low association. As expected – the group with multiple disabilities emerged as the one of those whose life was affected by the pandemic the most. Having more than one kind of these conditions greatly complicated coping with the daily problems caused by the pandemic. In this case, there are more requirements to be met for a disabled person in order take full advantage of a facility's services (e.g. banks).

5. Discussion and limitations

The study investigated a group of disabled persons who reported their feelings about their own mental health condition, their own perception of the quality of their lives and their opinions about the situation of disabled people during the pandemic.

Obviously, the surveyed group was not representative for the whole disabled population in Poland. First of all, the medium of the survey – the Internet – can be regarded as a crucial tool which can make a huge difference in the quality of life during a pandemic. Naturally, all the respondents had access to the Internet, which does not to have to be true for all disabled persons. Moreover, the survey was admitted to some forums for disabled people – participating in a forum of any kind is not a common feature of all people, disabled or not. Thus, merely these two factors – access to the Internet and participating in a forum – make respondents unrepresentative.

They are both privileged – having access to the Internet – and predisposed to become involved in social interactions such as participating in forums and surveys. Yet, although drawing conclusions about the whole population of disabled people based on the results of the survey would be unjustified, some interesting conclusions may provide leads for further surveys and policy planning.

Not surprisingly, it turned out that the strongest impact on the overall quality of life of the respondents came from those factors which were also perceived as those influencing to the highest degree their mental health.

The most striking result is that loneliness had twice as much impact as difficulties in meeting basic needs. Moreover, it was men who suffered more than women, probably due to better social skills of women who are more active in satisfying their own social needs.

Other crucial factors that are related to the feeling of the deteriorating quality of life (and probably causing it), are feeling abandoned by society, fears about a permanent worsening of their financial and health situation, and insufficient mental healthcare support. Moreover, education as well as financial situation, had a negative effect, namely decreasing their quality of life.

According to the Ministry of Health, it is estimated that up to 1.5 million people in Poland struggle with depression. However, according to the latest research, during the COVID-19 pandemic, this number could even double (NFZ, 2021). It is a well-known fact that depression causes many health issues, from mood swings even to suicide attempts. The pandemic situation makes it more difficult to cope with those disorders. Routines that were enforced by restrictions, deepen negative feelings and make overcoming depression very complicated. For some, that fight was lost. It turned out that “in contrast to previous years, younger people were more likely to undertake suicide attempts in the pandemic” (Medonet). Suicides have begun to affect young people to a great extent. Due to social media, their socialization skills are decreasing. They have a difficult time acquiring and maintaining new relationships. Moreover, their self-esteem has decreased due to the image of the ‘ideal life’ seen on the Internet. Switching stationary education to online classes has deepened the feeling of loneliness and social exclusion. One should mention the fact that not everyone has Internet access, 86.8% of the population of Poland uses the Internet (The World Bank). In many cases, the parents took over the education of the children who were completely cut off from their peers (the lockdown), which had a negative impact on their development, especially on those with disabilities, for whom a relationship with their group was crucial.

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JAKOŚĆ ŻYCIA OSÓB Z NIEPEŁNOSPRAWNOŚCIĄ PODCZAS PANDEMII COVID-19

Streszczenie: Na podstawie danych zebranych w ankiecie zbadano jakość życia osób z niepełnosprawnością podczas pandemii COVID-19. Zastosowano model logitowy, model liniowy, test chi-kwadrat oraz test istotności dla proporcji. Wykazano, że w czasie trwania pandemii główny wpływ na jakość życia osób z niepełnosprawnością miały zmienne, które opisywały pogorszenie stanu zdrowia psychicznego respondentów.

Słowa kluczowe: niepełnosprawność, jakość życia, pandemia, zdrowie psychiczne.