

A multicenter survey on the aspects of everyday life in adult patients with primary antibody deficiencies treated with immunoglobulin G replacement during the COVID-19 pandemic

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Abstract

Introduction: The COVID-19 pandemic has changed many aspects of everyday life. Patients with primary immunodeficiency (PID) are in a particularly difficult situation. The purpose of the present study was to contribute to the very limited research on the everyday aspects of functioning in PID patients during the COVID-19 pandemic.

Methods: The survey included 85 adult PID patients treated with immunoglobulin replacement therapy in four reference centers for immunology. Everyday functioning of the patients as well as their opinion concerning new solutions in medical care were analyzed.

Results: During the pandemic, the percentage of patients experiencing fear/anxiety has increased from 47% to 70%. The wide dissemination of information about the SARS-CoV-2 in the media has increased anxiety in 40% of the patients. Patients diagnosed with PID were most afraid of the exposure to contact with strangers, especially in public places. As many as 67 respondents (79%) considered the introduction of restrictions concerning social functioning as good. Only every fifth person learned about the pandemic from reliable sources. Eighty three percent of the patients receiving immunoglobulin substitution experienced less fear of SARS-CoV-2 infection. The patients positively evaluated the solutions related to the direct delivery of drugs to the place of residence in order to continue home IgRT therapy. Fifty three respondents (62.5%) believed that the possibility of a remote consultation was a very good solution.

Conclusion: It is necessary to increase educational activities concerning the pandemic provided by health care professionals, as patients obtain information mainly from the media and the Internet, which adversely affects the feeling of anxiety. The pandemic, in addition to the very negative impact on patients and the deterioration of their daily functioning, has made patients appreciate their life more, devote more time to family and friends, and do things they like.

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Keywords

primary immunodeficiencies, primary antibody deficiency, adult, SARS-CoV-2, COVID-19, fear, anxiety, medical care, quality of life, immunoglobulin treatment

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Introduction

The COVID-19 pandemic has affected many aspects of the lives of both healthy and ill people. Studies of the general population have shown a significant increase in pandemic-related stress, anxiety, and depression.^{1,2} Patients suffering from primary immunodeficiency (PID), who are at risk of infection from pathogenic microorganisms, even of low virulence, are in a particularly difficult situation.

There are limited data on the effects of the COVID-19 pandemic on PID patients.³ The aim of this study was to evaluate the functioning of adult PID patients with regard to selected aspects of everyday life and the functioning of health care during the COVID-19 pandemic.

Material and methods

Patients

The study covered the period from 1 June 2020 to 31 October 2020 and involved 85 patients over 18 years of age diagnosed with primary humoral immunodeficiency attending four reference immunological centers in Poland. The patients had been diagnosed with PID on the basis of the European Society for Immunodeficiencies (ESID)⁴ criteria and had attended scheduled in-person check-up visits to one of these centers during the study period. Before completing the questionnaire, all the patients had given their written consent to participate in the study. One patient who was offered to participate in the study refused to complete the questionnaire (the patient's data were not, therefore, included in further analysis). The study protocol was approved by an Ethics Committee at Collegium Medicum in Bydgoszcz (KB369/2020). The size of the study group is due to several reasons. First, we did not want to expose patients to an increased risk of infection. Therefore, we did not specifically invite patients to participate in the study. The questionnaire was filled in by the patients during the control visits. Additionally, it should be remembered that some patients with PID are treated in centers not included in the study and that PID is a relatively rare disease.

Data collection

The study was a questionnaire survey. The template of the questionnaire, patient information, and informed consent

used in this study are included in the supporting material. Patients completed the questionnaire on their own, and the data was processed in accordance with the General Data Protection Regulation. The questionnaire was developed by the researchers and consisted of 65 questions. The questions in the survey concerned patient functioning before and during the COVID-19 pandemic in terms of primary health care, specialist care in an outpatient clinic and an immunology center, as well as in the family and society. Particular emphasis was put on the assessment of different aspects of everyday life, such as leaving home for work, shopping, using public transport, being in places of worship, eating in restaurants, being in the company of complete strangers, being in the company of friends, with immediate family, and walking. A visual analog scales (VAS) was used for the evaluation, on which 0 meant no fear/anxiety and 10 corresponded to the most severe anxiety reaction.

It was not possible to use proven tools to assess the patients' quality of life due to the nature of the questions asked and the lack of similar analyses in the literature. The analysis conducted for this study aimed to indicate which aspects of everyday life and the functioning of the health service require further assessment. The authors of the article hope that in subsequent analyses they will be able to use proven tools to assess quality of life.

Statistical analysis

Statistical analysis was performed using the following methods: correlation between two variables, calculated by means of the Spearman's correlation coefficient; the non-parametric Mann-Whitney U test was used to evaluate the differences in one feature between two populations (groups); and the non-parametric Wilcoxon test, which is a non-parametric alternative to the Student's t-test, was used for related variables. All the calculations and figures were performed using Statistica 10.0 software and a Microsoft Excel spreadsheet using standard functions of this program. *p* values less than 0.05 were considered statistically significant.

Results

When examining the research results, it should be noted that completing the questionnaire was voluntary. The number of patients shown as lower than 85 in some analyses is due to respondents not answering some of the

questions. It was probably due to the fact that the treating physician knew the personal data of the patient filling in the questionnaire and/or the lack of willingness to answer some questions. Where the number of patients is shown to be greater than 85, this is due to the inclusion of multiple-choice questions.

Patients

The average age of the patients at the time of the research was 40.2 ± 13.9 years. Men accounted for 57.5%. The participation of patients with particular forms of immunodeficiency was as follows: 47 patients (55%) were diagnosed with common variable immunodeficiency; 17 patients (20%) with IgG subclass deficiency; eight patients (9%) with undifferentiated hypogammaglobulinemia; eight patients with agammaglobulinemia (seven patients [8%] X-linked; one patient [1%] autosomal recessive). Other immunodeficiencies were represented by individual patients: selective IgA deficiency, hyper-IgM syndrome, autoimmune lymphoproliferative syndrome, Nijmegen syndrome, and DiGeorge syndrome. All the patients, apart from those with selective IgA deficiency, received immunoglobulin supplementation, either intravenously (IVIG) (11 patients [13%]) or subcutaneously (SCIG) (74 patients [87%]).

At the time the questionnaire was completed, none of the patients had been infected with SARS-CoV-2, and in the case of three patients, people from their environment had had COVID-19 before.

Sociodemographic data

Of the patients who participated in the study, 65 (76.5%) lived with their family, six (7%) lived with a partner, and 14 (16.5%) lived alone. Seventy-eight respondents (92%) assessed their housing conditions as good, six (7%) as satisfactory, and one (1%) as unsatisfactory. Forty-two patients (49.5%) had a university degree, and 33 (39%) had received secondary, three (3.5%) vocational, and six (7%) primary education. Fifty patients (59%) were professionally active (41 [48%] were white-collar workers), 14 (16.5%) received a disability pension, five (6%) a retirement pension, five (6%) were still studying, and six (7%) were unemployed. Two patients (2%) chose the option “other”, while 3 (3.5%) patients did not answer this question. Thirty of the employed patients (60%) had the opportunity to work remotely.

Sources of knowledge about the pandemic

The patients obtained information about SARS-CoV-2 from the following sources (there was a choice of several options): 45 patients (53%) from the Internet (from

Internet portals, including social networks); 31 (36.5%) from television; 13 (15.5%) from a doctor; 10 (12%) from reliable sources (e.g., scientific publications, government health Internet sites); and six (7%) from their families. Information regarding SARS-CoV-2 infection was checked by the patients with the following intensities: 45 patients (53%) checked once a day; 15 (17.5%) several times a day; 15 (17.5%) once a week; eight (9.5%) less than once a week; and one (1%) over a dozen times a day. One patient (1%) did not follow information about the pandemic at all.

Seventy-five patients (88%) did not feel the need to look for additional telephone information on the SARS-CoV-2 pandemic from their general practitioner (GP). Ten respondents (12%) took the opportunity to gain information: five of them believed that their GP had provided them with partially exhaustive information; three thought that they had been given non-exhaustive information on COVID-19 by their GP; and two patients considered that the doctor had provided them with comprehensive information. No patient chose the option that he tried but could not contact his GP. Twenty-nine patients (34%) made additional telephone calls to their clinical immunologist for advice on SARS-CoV-2 infection; 55 patients (65%) did not do so; and one (1%) tried but was impossible. Eighteen of the 29 patients (62%) who contacted their clinical immunologist reported that the doctor had given them comprehensive information; nine respondents (31%) stated that the physician had provided them with partially exhaustive information; and two (7%) that they had not been given exhaustive information.

Fear of COVID-19 infection

The average intensity of fear of coronavirus infection on a scale from 0 to 10 was 3.39 ± 2.44 points. Women declared statistically significantly higher levels of fear compared to men (4.14 ± 2.63 vs 2.83 ± 2.17 ; $p = 0.018$). Fear of infection with the new virus correlated significantly with the age of the patients ($R = 0.277$; $p = 0.011$). Its intensity in particular age groups was as follows: 2.9 ± 2.15 in the group of 18–30-year olds; 2.32 ± 2.28 among 31–40-year olds; 4.17 ± 2.41 among 41–50-year olds; and 4.4 ± 2.5 among those over 50 years of age. Fear of infection did not correlate with the patient’s level of education.

To the question: “How does such a widespread dissemination of information about SARS-CoV-2 in the media affect you?” the respondents replied: intensifies my anxiety—34 patients (40%), it does not affect me at all—37 patients (43.5%). During the pandemic, patients with PID reported fearing the following the most (multiple-choice questions): a severe course of infection: 50 patients (59%); coronavirus infection among loved ones: 48 (56%); their own coronavirus infection: 45 (53%); death from COVID-19: 29 (34%); leaving their loved ones: 18 (21%);

Table 1. Intensity of fear of everyday activities before and during the epidemic.

Fear:	N	Before the epidemic		During the epidemic		p
		Average	SD	Average	SD	
of being infected with any pathogen	85	3.2	2.553	3.84	2.802	<0.001
of leaving home for work	77	1.61	2.135	3.51	2.891	<0.001
of doing the shopping	85	1.44	1.918	3.75	2.781	<0.001
of being in public transport	83	1.99	2.511	4.84	3.09	<0.001
of using other public places	84	2.00	2.385	4.85	2.947	<0.001
of being in places of worship	81	1.64	2.325	4.49	3.131	<0.001
of having a meal in a restaurant	84	1.35	2.085	4.27	3.194	<0.001
of being in the company of complete strangers	85	1.72	2.428	4.79	3.048	<0.001
of being in the company of friends	85	0.87	1.844	3.21	2.891	<0.001
of being with the group of immediate family	85	0.52	1.368	1.89	2.405	<0.001
of walking	84	0.50	1.427	2.15	2.326	<0.001

hospitalization: 14 (16%); dyspnea/lack of air: 11 (13%); the necessity of staying in an intensive care unit: 9 (11%); and social rejection: four (5%).

Anxiety level

During the pandemic, the percentage of patients experiencing fear/anxiety increased from 47% (40 patients) to 70.5% (60 patients). During the pandemic, 12 patients (14%) experienced anxiety every day, 26 (30.5%) experienced it once a week, and 22 (26%) at least once a month. Before the outbreak of the pandemic, these values were as follows: 11 patients (13%), 13 patients (15%), and 16 patients (19%), respectively. Forty-five patients (53%) did not feel fear/anxiety prior to the pandemic, compared to 25 patients (29.5%) in the pandemic period.

Although no differences in the intensity of fear between men and women were observed before the pandemic, during the pandemic, women experienced anxiety statistically significantly more often compared to men. Both before and during the pandemic, no significant correlation was found between the anxiety experienced and the age or education of the surveyed patients.

Fifteen patients (17.5%) declared that they had experienced a panic attack, defined as severe anxiety without any specific cause, accompanied by excessive sweating, palpitations and trembling hands. Twenty patients (23.5%) contacted a specialist (e.g., a psychiatrist, psychologist, or psychotherapist) due to anxiety and were taking prescribed anxiolytics (e.g., hydroxyzine, diazepam, or alprazolam).

Mood

Before the COVID-19 pandemic, 67 patients (80%) assessed their mood as normal, five patients (6.0%) as elevated, and 12 (14%) as lowered. After the outbreak of the pandemic, the number of patients declaring a normal mood

decreased to 51 (60.5%). During the same period, the number of patients who described their mood as lowered (22; 26%) or elevated (11; 13%) increased. However, these differences were not statistically significant. There were also no statistically significant differences in the declared mood between men and women, both before and during the pandemic. In neither period was a significant correlation found between perceived mood and age or education level.

Aspects of everyday life

Table 1 compares the average intensity of fear declared by the patients who participated in the study (marked on a scale from 0 to 10) connected with performing selected activities of everyday life before and during the pandemic period. Before the outbreak of the pandemic, patients with PID were most afraid of being infected with any pathogen. At the time, other aspects of everyday life aroused little fear in this group of patients. During the pandemic, PID patients were most afraid of exposure to contact with strangers, especially on public transport and in public places. For each aspect of everyday life evaluated, there was a significant increase in the average intensity of fear. The greatest difference was observed in the fear of contact with strangers and of being in public places, such as public transport, places of worship, or restaurants.

Both before and during the pandemic, women experienced more intense fear associated with the aspects of everyday life analyzed than men, but only in selected cases were the differences statistically significant. Before the outbreak of the pandemic, this concerned the fear of contamination with any pathogen and having a meal in a restaurant. However, during the pandemic, statistically significant differences between the sexes were observed in relation to fear of infection with any pathogen, being in the company of strangers and friends, and walking (Table 2).

Table 2. Average intensity of fear connected with selected aspects of everyday life in men and women before and during the epidemic.

Fear:	Before the epidemic					During the epidemic				
	Female		Male		P	Female		Male		p
	Average	SD	Average	SD		Average	SD	Average	SD	
of being infected with any pathogen	4.03	2.94	2.59	2.05	0.027	4.89	2.96	3.06	2.43	0.005
of leaving home for work	2.14	2.23	1.29	2.03	0.08	4.38	3.12	2.98	2.64	0.053
of doing the shopping	1.78	1.97	1.18	1.86	0.072	4.36	2.90	3.31	2.63	0.097
of being in public transport	2.44	2.89	1.67	2.18	0.225	5.44	3.28	4.43	2.92	0.124
of using other public places	2.57	2.62	1.59	2.14	0.074	5.37	3.09	4.47	2.81	0.155
of being in places of worship	2.11	2.54	1.28	2.10	0.077	5.17	3.32	3.98	2.91	0.065
of having a meal in a restaurant	1.63	1.91	1.14	2.2	0.036	5.09	3.34	3.69	2.99	0.059
of being in the company of complete strangers	2.22	2.71	1.35	2.16	0.101	5.67	3.15	4.14	2.83	0.021
of being in the company of friends	1.19	2.34	0.63	1.35	0.449	4.08	3.13	2.57	2.55	0.028
of being with the group of immediate family	0.58	1.52	0.47	1.26	0.996	2.47	2.77	1.47	2.02	0.117
of walking	0.77	1.86	0.31	0.98	0.286	2.69	2.26	1.78	2.32	0.043

Table 3. Correlation of the intensity of fear connected with selected activities of everyday life with age and the level of education.

Fear	Age					Education				
	N	Before the epidemic		During the epidemic		N	Before the epidemic		During the epidemic	
		R	p	R	P		R	p	R	p
of being infected with any pathogen	85	0.3	0.005	0.268	0.013	84	-0.053	0.629	0.016	0.882
of leaving home for work	77	0.338	0.003	0.199	0.083	76	0.028	0.811	0.144	0.214
of doing the shopping	85	0.292	0.007	0.232	0.032	84	-0.166	0.131	-0.01	0.926
of being in public transport	83	0.291	0.008	0.222	0.043	82	0.047	0.675	0.199	0.074
of using other public places	84	0.253	0.02	0.257	0.018	83	-0.04	0.72	0.103	0.354
of being in places of worship	81	0.267	0.016	0.313	0.004	80	0.014	0.9	0.191	0.09
of having a meal in a restaurant	84	0.365	0.001	0.405	<0.001	83	-0.02	0.856	0.124	0.264
of being in the company of complete strangers	85	0.217	0.046	0.299	0.005	84	-0.229	0.036	-0.001	0.993
of being in the company of friends	85	0.197	0.071	0.29	0.007	84	-0.137	0.215	0.005	0.967
of being with the group of immediate family	85	0.168	0.124	0.307	0.004	84	-0.044	0.689	0.057	0.604
of walking	84	0.144	0.191	0.282	0.009	83	-0.011	0.921	-0.031	0.783

Analysis of the correlation between the intensity of fear related to everyday activities and age revealed a statistically significant positive relationship (the older the patients, the more fear they experienced) in the case of almost all activities evaluated, both before and during the pandemic (Table 3). Both before and during the pandemic, age most strongly correlated with the intensity of fear of having a meal in a restaurant. Before the pandemic, age did not significantly correlate with the declared intensity of fear of being in the company of friends, being with the immediate family group, and walking. On the other hand, during the pandemic, only in the case of fear of leaving home for work was no statistically significant correlation with age observed. Education level significantly correlated only with the intensity of fear of being in the company of complete

strangers before the pandemic ($R = -0.229$; $p = 0.036$) (i.e., the more educated the patients, the less fear/anxiety they experienced).

From all the methods of coping with stress given in the questionnaire, the patients chose the following (it was possible for them to select more than one answer): physical activity: 41 patients (48%); meeting with their families: 40 (47%); meeting friends: 36 (42.5%); reading books: 35 (41%); psychotherapy: 10 (12%); and relaxation techniques: 10 (12%). Eleven patients (13%) mentioned other forms of coping with stress, such as phone calls with family and friends, prayers, sewing, crocheting, knitting, computer games, board games, using the Internet, hobbies, listening to music, and antidepressants. Three respondents (3.5%) stated that they could not cope with stress.

Interestingly, as many as 30 patients (35%) began to devote more time to family and friends; 22 (26%) began to appreciate life more; and 19 (22%) began to do things they like.

Protective measures and acceptance of restrictions

During the pandemic, the respondents used the following personal protective measures (there was a possibility of choosing more than one option): reusable cloth mask: 60 patients (71%); surgical mask: 44 (52%); isolation from the environment: 29 (34%); isolation from interpersonal contact: 26 (31%); mask with a specialist filter: 15 (18%); face shield: five (6%); and home isolation: five (6%).

Sixty-seven respondents (79%) believed that introducing restrictions on social functioning was good, five (6%) considered that such limitations were not necessary, and three (4%) stated that the problem had never existed and was exaggerated.

New aspects of medical services

During the pandemic, the average intensity of fear of a scheduled appointment at the immunology clinic was 2.02 ± 2.445 points and of hospitalization in the immunology department 2.66 ± 2.710 points. The sex, age, and education of the respondents did not show statistically significant correlation with the results of the fear experienced of a scheduled appointment at the immunology clinic or hospitalization in the immunology department.

Seventy patients (83%) receiving immunoglobulin substitution experienced less fear of being infected with SARS-CoV-2 as a result of the supplementation. When asked if the administration of immunoglobulins improved the patient's comfort in terms of fear of coronavirus infection, 29 respondents (34%) answered yes to a large extent, 29 (34%) to a moderate extent, and 12 (14%) to a small extent.

During the pandemic, the possibility of making a remote appointment or having a traditional visit was introduced. Fifty-three respondents (62.5%) found the possibility of a remote appointment a very good solution; 22 (26%) did not have an opinion; nine (10.5%) stated that such a solution did not work for patients with immunodeficiency; and one patient (1%) did not answer this question. Sixty-six patients (77.5%) did not take advantage of a remote appointment but 19 (22.5%) did. None of the patients chose the option "I tried but it was impossible."

The possibility of an authorized person collecting medicines for home treatment or home delivery of drugs was also introduced. Sixty-three patients (74%) thought it was a very good solution; 18 (21%) had no strong opinion; one person (1%) thought it was a bad solution; and three persons (4%) did not answer this question. Twenty-seven

respondents (32%) took advantage of the option of having an authorized person collect their drugs. Only three (3.5%) did not have this possibility, but if they did, they would be happy to use it. During the study, 29 patients (34%) had the possibility of home delivery of drugs, and 49 (57.5%) would be interested in such a solution continuing after the pandemic.

Discussion

The unprecedented pandemic situation poses a challenge for the healthcare system and is a particular burden for chronically ill patients. The present study provides important information on the impact of the COVID-19 pandemic on the daily life of patients with PID. Knowledge available on the course of COVID-19 in this heterogeneous group of patients is still limited, and the data are ambiguous.⁵

The study group of patients had a zero COVID-19 rate, which requires clarification. The analysis concerned the first wave of the pandemic, which occurred later in Poland compared to other countries. Precautions were already being taken with PID patients before the pandemic due to the increased risk of infection from any pathogen. The introduction of remote appointments also made it possible to limit contact with the health service. In Poland, patients with PID who qualify for immunoglobulin substitution are admitted on different dates to other patients and the distance and hour regimes are respected (additional author's comment: as of the date of final approval of the article for publication, the percentage of people infected with the SARS-CoV-2 virus was close to 30%, but fortunately most infections were mild). A comparison of the number of COVID-19 cases in Poland and around the world during the study period is presented in [Figure 1](#).^{6,7}

Most patients in the study group led an active professional life, despite a chronic illness, and had at least secondary education. During the pandemic, there was a significant increase in the intensity of fear for each aspect of everyday life evaluated, especially of contact with strangers and being in public places. The results of our research indicate more severe anxiety and stress related to the pandemic in women with PID, which is consistent with the results of studies in the general population.⁸ Based on the analyses available in the literature thus far, in the population of patients with chronic diseases, a higher level of fear of COVID-19 occurs in patients with primary education.⁹ In our study, the level of education correlated significantly only with the intensity of fear of being in the company of people who were complete strangers before the pandemic (i.e., the more educated the patients, the less fear/anxiety they felt). The pandemic, in addition to the very negative impact on patients and the deterioration of their daily functioning, has made patients appreciate their life

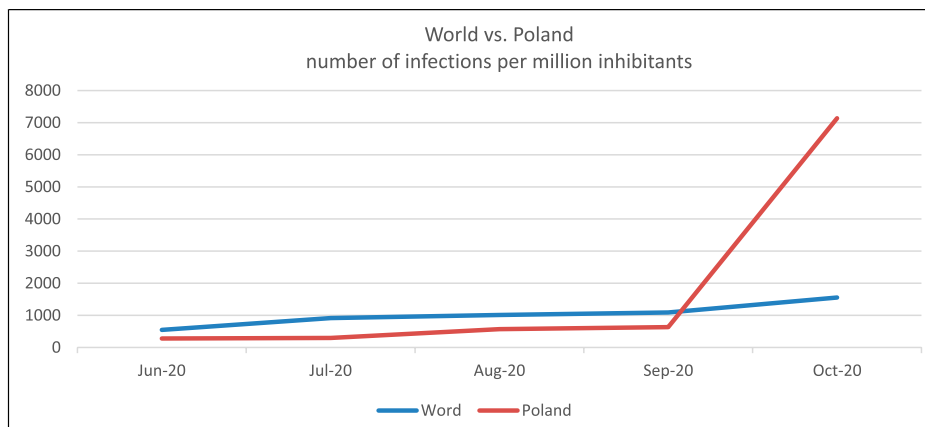


Figure 1. Comparison of the incidence of COVID-19 in Poland and in the world during the period of study.

more, devote more time to family and friends, and do things they like. It is worrying that on the one hand, the widespread dissemination of information about SARS-CoV-2 by the media increased anxiety in as many as 40% of the patients, and on the other, the media and the Internet were the main sources of information about the pandemic for the patients.

The patients with PID who participated in the study were aware of being exposed to a higher risk of infection even before the COVID-19 pandemic, which could have led to the acceptance of restrictions introduced during the pandemic by most of them. Only three patients considered the problem to be exaggerated.

Our aim was also to evaluate solutions in the healthcare system from the perspective of adult patients with PID. Even before the pandemic period, most patients had been treated with SCIG or facilitated SCIG (fSCIG) as home therapy as part of the therapeutic program. In accordance with the rules of drug reimbursement before the pandemic, the patients were obliged to visit their treatment center at least every 12 weeks.¹⁰ IVIG treatment was possible only in hospital conditions. During the pandemic, many hospitals, including those with PID treatment centers, were also dedicated to the care of patients with COVID-19.

PID patients, to a large extent, associated their safety with the continuation of immunoglobulin replacement therapy (IgRT) and one of their greatest concerns was the limited availability of treatment.¹¹⁻¹³ The results of our study confirm that 83% of those receiving IgRT experienced less fear of SARS-CoV-2 infection as a result of the supplementation.

In March 2020, measures were introduced in Poland to allow healthy people authorized by patients to collect medications from the centers on their behalf. It was also possible to deliver medicines to patients' homes and to activate remote assistance services. These tools allowed patients to avoid traveling, prevented the spread of infection, and enabled uninterrupted care for established

patients. These activities were analogous to the solutions in Italian centers.³ The evaluation of these opportunities from the patients' perspective was positive and they were interested in maintaining these after the pandemic has ended.

Our study has certain limitations. It involves a small group of patients, but it should be remembered that PIDs are rare illnesses. We conducted the study at the beginning of the pandemic, when it was still the case that few patients had someone affected by SARS-CoV-2 infection in their environment. We did not use validated questionnaires to evaluate the aspects of patients' life and anxiety, which makes it more difficult to compare the results with other publications. It was not possible to use proven tools to assess the patients' quality of life due to the nature of the questions asked and the lack of similar analyses in the literature. Nevertheless, thanks to the degree of detail contained in the survey, we had the opportunity to assess numerous aspects of everyday life and were able to learn patients' opinions on specific solutions that had not been used in the healthcare system before. Our study is the first of its kind carried out among Polish patients with PID.

Conclusions

The COVID-19 pandemic has increased PID patients' fear of numerous everyday activities. This fear may have been due, among other things, to a large proportion of the patients deriving their knowledge from the media and the Internet. This indicates the need for increased educational activity by professional medical staff caring for patients with PIDs. Special attention should be paid to the correct use of personal protective equipment and hygiene principles.

Although the patients with PID were satisfied with their specialist care, they raised concerns about the cooperation of primary health care during the course of a pandemic. The results of our analysis also indicate the need for better access to psychologists and psychiatrists.

Continuation of treatment with IgRT also increased the patients' sense of safety in the context of SARS-CoV-2 infection. Patients with PID who receive IgG substitution permanently had a positive perception of the possibility of remote appointments, an authorized person collecting their medicines on their behalf, and home deliveries of medicines, which were approaches introduced at the beginning of the pandemic. Consideration should be given to continuing these measures even after the epidemiological threat has passed.

The pandemic has, however, in addition to the very negative impact on patients and a deterioration in their daily functioning, made those patients who participated in our study appreciate their life more, devote more time to family and friends, and do things they like.

Author Contributions

All named authors meet the International Committee of Medical Journal Editors (ICMJE) criteria for authorship for this article, take responsibility for the integrity of the work as a whole, and have given their approval for this version to be published.

Declaration of conflicting interests

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Ethical approval

Ethics approval Ethical approval for this study was obtained from Bioethical Commission of the Nicolaus Copernicus University in Toruń at Collegium Medicum im. Ludwik Rydygier in Bydgoszcz (APPROVAL NUMBER/ID)*: KB369/2020.

Informed consent

Written informed consent was obtained from all subjects before the study. All the patients had given their written consent to participate in the study.

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