


Marta Freitas Olim* <https://orcid.org/0000-0001-5151-9425>**Sónia Guadalupe**** <https://orcid.org/0000-0003-4898-3942>**Mónica Carvalho***** <https://orcid.org/0000-0003-1875-8592>**Paula Fragoso****** <https://orcid.org/0000-0002-8004-4905>**Susana Ribeiro******* <https://orcid.org/0000-0003-1406-6070>**Susana Torres******* <https://orcid.org/0000-0001-8842-4454>**Dora Isabel Dias******* <https://orcid.org/0000-0003-4835-0045>**Fernando Macário*******

* Social Worker. Director of the Social Work Department of Diaverum Portugal. Graduated and Master in Social Work, e-mail: marta.olim@diaverum.com

** Social Worker. Assistant Professor of Social Work in Miguel Torga Institute of Higher Education, Coimbra, Portugal. PhD in Social Work, PhD in Mental Health. Researcher in CEISUC – Centre for Health Studies and Research of the University of Coimbra, e-mail: soniaguadalupe@gmail.com

*** Social Worker at Diaverum Portugal. Graduated in Social Work. Master in Social Work: Welfare and Social Management, e-mail: monica.carvalho@diaverum.com

**** Social Worker at Diaverum Portugal. Graduated in Social Work, e-mail: Paula.Fragoso@diaverum.com

***** Social Worker at Diaverum Portugal. Graduated in Social Work and Sociology, e-mail: Susana.Ribeiro@diaverum.com

***** Social Worker at Diaverum Portugal. Graduated in Social Work, e-mail: Social.Aveiro@diaverum.com

***** Social Worker at Diaverum Portugal. Graduated in Social Work, e-mail: Dora.Dias@diaverum.com

***** Physician. Graduated in Medicine. Specialist in Nephrology. Medical Management of Diaverum Iberia, Chief Medical Officer of Diaverum, e-mail: Fernando.macario@diaverum.com

SOCIAL IMPACT OF COVID-19 ON CKD PATIENTS ON DIALYSIS TREATMENT DURING PANDEMIC IN PORTUGAL

Abstract. This study aimed to assess the social impact of COVID-19 on chronic kidney disease patients, a vulnerable population, by analysing the social problems that emerged and aggravated during the pandemic's first phase. 117 CKD patients on treatment, referred to Social Work, participated in this study. New referrals were 37.6%, and 62.4% were aggravated situations, presenting mostly economic deprivation or lack of income, unemployment, and social isolation. The social intervention complexity was higher among those with aggravated social problems. The results allow social workers to plan interventions focused on the most relevant emerging issues in a pandemic challenging context.

Keywords: COVID-19 pandemic, CKD, haemodialysis, social needs, social work.

1. Introduction

The COVID-19 pandemic is considered to be the greatest global health crisis of our time, constituting a critical conjuncture with repercussions on the physical, psychological, social, environmental and economic dimensions of human life (Cruz et al. 2020).

The economic and financial repercussions that also derive from this pandemic context are yet to be assessed, namely a rise in the worldwide unemployment rate and an increase in global poverty (Sumner et al. 2020). The impact and duration of the economic crisis on individuals and families resulting from a pandemic are difficult to predict, which creates uncertainty in various areas of life in society (Bhattacharya 2020; Martin et al. 2020). However, the history of pandemics reveals that they disproportionately affect the poor and disadvantaged, indeed, "pandemics rarely affect all people in a uniform way" (Ahmed et al. 2020: 240).

The constraints of the pandemic and lockdown and other safety measures will impact more deeply on previously vulnerable populations, namely the chronically ill, particularly individuals with chronic kidney disease (Novick et al. 2020; Saqib et al. 2020), who are the focus of this article, even though patients with or at risk of kidney disease are disproportionately affected by the consequences of the COVID-19 pandemic (Bruchfeld 2021). This is a population more at risk of contracting COVID-19, as a result of being immunosuppressed and their advanced age (Collado et al. 2020), and also due to the circumstances of the disease and treatment itself (e.g., difficulties in keeping physical distance during treatment, the use of public transport to travel to treatments).

Patients with CKD already live a challenging daily context that is reflected in multiple needs of the disease to which a vulnerable social situation is added

(Olim et al. 2018a; Olim et al. 2018b). The unpredictable and uncertain nature of the pandemic can potentiate situations of vulnerability and social risk.

The psycho-social distress associated with preventive and confinement measures is also relevant (Bhattacharya 2020). The circumstances experienced in pandemic daily life can lead to loss of autonomy and increased distress, namely sadness and anxiety, in chronic patients with dialysis, which tend to worsen with the impact of the pandemic (Lee et al. 2020; Sousa et al. 2021). Although distress may constitute an adaptive response in contexts marked by unpredictable changing conditions (Dubey et al. 2020), we should emphasize the fear of being infected due to high-risk condition of CKD patients, specifically in the dialysis unit (Sousa et al. 2021), which tends to punctuate patients' lives, affecting their daily life and modifying human relations and leading to social isolation (Saladino et al. 2020).

In order to understand in greater depth the social problems and needs felt by chronic renal failure patients during the first phase of the COVID-19 pandemic, the study aims to identify the social problems that emerged and aggravated during this period, as well as to analyse the interaction with the support needs diagnosed by Social Work, the response to the problematic situations of this population and the level of complexity associated with social intervention.

2. Material and methods

2.1. Method and procedures

The study is descriptive and presents a transversal cohort. A non-probabilistic sample of 117 people with chronic kidney disease living in Portugal undergoing haemodialysis treatment during the first phase of the COVID-19 pandemic participated in the study. Data were collected from March 1, 2020 to September 30, 2020 by social workers working in dialysis clinics in Portugal (26 clinics from the North, Centre to Lisbon and Tagus Valley geographic areas) as strategic informants. The period refers to the first wave of the COVID-19 pandemic in Portugal. The sample included patients meeting the following criteria: 1) patients who were being monitored by Social Work and whose social situation aggravated during the period under analysis; 2) patients representing new situations flagged by themselves or by the social assessment of Social Work; 3) patients referred to Social Work by the interdisciplinary team. Patients with requests for transportation support were excluded. The sample of 117 participants was part of a universe of 2627 patients monitored in the 26 clinics in the same period, representing 4.5% of the total number of patients.

All patients, upon entering the clinics, signed an informed consent to be treated and assisted by an interdisciplinary team, in which they agreed to the use

of data for research purposes. Data collection was carried out by social workers by means of semi-structured interviews, conducted in person and by telephone, for individual and family assessment, which were later systematized in an anonymous database. Social workers are guided by an international code of ethics that requires respect for confidentiality and privacy, and patient safety was also respected when conducting interviews and deontological and ethical guidelines for practice during COVID-19 Pandemic were considered (IFSW 2020).

2.2. Participants

117 patients on haemodialysis treatment participated in the study. The sample includes 53 women (45.3%) and 64 men (54.7%), with an average age of 60 years. Most of the patients have completed primary school (51.3%), which corresponds to 4 years of education, followed by those who have completed elementary and secondary school (10.3% and 12.8%, respectively). 12.0% have no school education and only 6.8% have completed higher education. Most participants are part of nuclear families with children (40.2%) (Table 1).

Table 1. Socio-demographic and socio-familiar characteristics of participants

	<i>N</i>	%
	117	100
Sex		
Female	53	45.3
Male	64	54.7
Age ($M = 60,18$; $SD = 16,62$; $Min = 22$; $Max = 90$)		
< 40 years old	17	14.5
40–64 years old	50	42.7
65–74 years old	22	18.8
>= 75 years old	28	23.9
Qualifications		
No Schooling	14	12.0
Primary School (1st–4th grade)	60	51.3
Elementary School 2nd Cycle (5th–6th grade)	12	10.3
Elementary School 3rd Cycle (7th–9th grade)	15	12.8
Secondary School/Professional Course (10th/12th grade)	8	6.8
Higher Education (Bachelor's, Degree and Doctorate)	8	6.8
Nuclear Family		
Nuclear Family with children	47	40.2
Nuclear Family without children	2	1.7

Single-Person Family (lives alone)	22	18.8
Extended Family	20	17.1
Single-Parent Family	12	10.3
Reconstituted Family	3	2.6
Cohabiting Family and Other Types	6	5.1
Living in an Institution	5	4.3

Source: Authors own elaboration.

2.3. Instruments

The data were systematized from Social Work's processes, and were obtained through semi-structured interviews of social diagnosis and follow-up conducted by social workers. The socio-demographic and family variables were obtained from the social processes, as well as the social problems, the social needs identified, and the type of response in the social intervention process.

The ICAPIS_DRC complexity index calculated from the Matrix of Complexity Associated with the Process of Social Intervention with Chronic Renal Patients (MCAPIS_DRC) was also used (Olim et al. 2019). The Matrix is a hetero-administered instrument that allows assessing the complexity associated with the process of social intervention in the area of Nephrology, comprising fifteen indicators grouped into two dimensions: 1) Determinants of intervention complexity related to health (with seven indicators); 2) Determinants of intervention complexity related to the psychosocial situation (with eight indicators). Each indicator is classified into levels of complexity using a three-point *Likert* scale: low, medium, and high. The ICAPIS_DRC ranks the MCAPIS_DRC total score through the following cut-off points and complexity levels: 1) Low ≤ 31.22 ; 2) Medium = 31.23-38.56; 3) High ≥ 38.56 (Olim et al. 2019).

2.4. Statistical analysis

The statistical analysis used the software *IBM-SPSS Statistics* version 25.0. Descriptive and inferential statistics were used in data analysis. In the univariate description of the variables, we used measures of central tendency and dispersion. The chi-square test was used to verify the association between variables, complemented with Cramer's V and Phi tests to assess the intensity of the association. The Kolmogorov-Smirnov test was used to assess the normality of the distribution of variables, and the assumptions of the t-test were verified to assess differences between the means of the subsamples.

3. Results

From March to September 2020, 117 patients with situations that presented associated social problems were reported to Social Work, where 37.6% ($n = 44$) of the cases corresponded to situations referred to Social Work for the first time. Most of the situations (62.4%; $n = 73$) were patients previously followed by Social Work whose social situations aggravated due to the emergence of additional problems or the worsening of the diagnosed problems (Table 2).

Table 2. Social situation of patients assessed by Social Work during COVID-19 pandemic

	<i>N</i>	%
	117	100
Social situation of patients		
New situation: New social problems identified	44	37.6
Aggravated situation: Situation in follow-up with new diagnosed problems or worsening of problems	73	62.4

Source: Authors own elaboration.

When we analysed the type of social problems that emerged in this challenging context, we realized that most of them are related to economic need and/or lack of income ($n = 47$; 40.2%), followed by unemployment ($n = 17$; 14.5%), and by family and social isolation ($n = 14$; 12.0%). The identified needs were mostly for material, instrumental support ($n = 61$; 52.1%), implying social benefits, followed by support needs from the secondary network ($n = 29$; 24.8%). We verified that most of the needs were addressed ($n = 59$; 50.4%), even though 38.5% ($n = 45$) were still waiting for a definitive answer (Table 3).

Table 3. Social problems and support needs

	<i>N</i>	%
	117	100
Diagnosed social problems		
Economic Deprivation/Lack of Income	47	40.2
Unemployment	17	14.5
Homelessness	6	5.1
Family and Social Isolation	14	12.0
Family Violence	8	6.8
Family Overburdening	9	7.7
Difficulty or inability to provide care	10	8.5

Anxious and Depressive Manifestations	4	3.4
Addictive Habits	1	.9
Legalization of Documents	1	.9
Support Needs		
Advocacy and Psychosocial Intervention	19	16.2
Secondary Network Support	29	24.8
Material and/or Instrumental Support	61	52.1
Occupation	8	6.8
Subsequent Evaluation of the Response and the Situation		
Adequate Response	59	50.4
Patient Non-adherence	1	.9
Family Non-Adherence	1	.9
Inadequate Response	1	.9
No Response	6	5.1
Awaiting response	45	38.5
Discharge	2	1.7
Death	2	1.7

Source: Authors own elaboration.

Concerning the association between social problems according to new or previously monitored situations, we found that the most relevant issue in both sub-samples was economic deprivation/lack of income, representing 38.6% of the problems in new situations and 41.1% in aggravated situations. Unemployment is also a relevant issue in both sub-samples (13.6% and 15.1%). However, family and social isolation emerges as the second most represented issue in the sub-sample of patients with a new social situation. The distribution of support needs according to sub-samples is similar, with the need for material and instrumental support being the most common in both groups of patients. The distribution of the categories of diagnosed problems and social needs according to the sub-samples did not show a statistically significant association ($p > 0.05$) (Table 4).

Table 4. Contingency between problems and social needs according to a social situation

	New social situation		Aggravated social situation		<i>Statistical Tests</i>
	<i>N</i> = 44	%	<i>N</i> = 73	%	
Diagnosed social problems					
Economic Deprivation/Lack of Income	17	38.6	30	41.1	
Unemployment	6	13.6	11	15.1	
Homelessness	1	2,3	5	6.8	
Family and Social Isolation	7	15.9	7	9.6	Chi-square 7.696
Family Violence	3	6.8	5	6.8	<i>p</i> = .565
Family Overburdening	2	4.5	7	9.6	Cramer's V .256
Difficulty or inability to provide care	4	9.1	6	8.2	<i>p</i> = .565
Anxious and Depressive Manifestations	3	6.8	1	1.4	
Addictive Habits	0	.0	1	1.4	
Legalization of Documents	1	2.3	0	0.0	
Support Needs					
Advocacy and Psychosocial Intervention	6	13.6	13	17.8	Chi-square .374
Secondary Network Support	11	25.0	18	24.7	<i>p</i> = .946
Material and/or Instrumental Support	24	54.5	37	50.7	Cramer's V .057
Occupation	3	6.8	5	6.8	<i>p</i> = .946

Source: Authors own elaboration.

We can observe that in situations of economic deprivation, unemployment and homelessness, needs for material and instrumental support are mostly identified. For the problem of family and social isolation, the social workers identify needs for psychosocial intervention, support from the secondary network with the possibility of responding to this type of problem and material and instrumental support. The need for support from the secondary network was especially relevant in situations of difficulty or inability to provide care, as well as family overburdening. There is very strong evidence of the contingency between variables ($p < 0.001$) (Table 5).

When the level of complexity associated to the process of social intervention with the participants was evaluated, the majority presented medium complexity ($n = 60$; 51.3%), followed by low complexity ($n = 36$; 30.8%) and high complexity ($n = 21$; 17.9%). Among new and unprecedented situations in relation to social problems, low complexity levels were more frequently found when compared to aggravated situations (45.5% vs. 21.9%). On the other hand, situations of high complexity were more frequent among cases with aggravated problems relative to new cases (27.4% vs. 2.3%). Moderate levels of complexity appeared as the most frequent in both groups with similar percentages (52.3%

and 50.7%). There is a very strong evidence of significant association between ICAPIS_DRC levels and the situation ($p < 0.001$) (Table 6.). The group with the highest average level of complexity is the aggravated social situations group, with very strong evidence of significant differences between the means in the subsamples ($M = 35.86$ vs. $M = 32.36$; $p < 0.001$) (Table 6).

Table 5. Contingency between social problems and support needs

	Support Needs				Statistical Tests
	Advocacy and Psychosocial Intervention	Secondary Network Support	Material and/or Instrumental Support	Occupation	
Diagnosed social problems	n %	n %	n %	n %	
Economic Deprivation/ Lack of Income	2 1.7%	9 7.7%	34 29.1%	2 1.7%	
Unemployment	1 .9%	3 2.6%	8 6.8%	5 4.3%	
Homelessness	0 .0%	0 .0%	5 4.3%	1 .9%	
Family and Social Isolation	4 3.4	4 3.4	6 5.1%	0 .0%	Chi-square 67.203 $p = .000$
Family Violence	4 3.4%	2 1.7%	2 1.7%	0 .0%	
Family Overburdening	3 2.6%	4 3.4%	2 1.7%	0 .0%	Phi .758 $p = .000$
Difficulty or inability to provide care	2 1.7%	7 6.0%	1 .9%	0 .0%	
Anxious and Depressive Manifestations	1 .9%	0 .0%	3 2.6%	0 .0%	
Addictive Habits	1 .9%	0 .0%	0 .0%	0 .0%	
Legalization of Documents	1 .9%	0 .0%	0 .0%	0 .0%	

Notes: % for the total.

Source: Authors own elaboration.

Table 6. MCAPIS_DRC and ICAPIS_DRC according to patients' social situation

	Total				New social situation				Aggravated social situation				Statistical Tests
	<i>M</i>	<i>SD</i>	<i>Min</i>	<i>Max</i>	<i>M</i>	<i>SD</i>	<i>Min</i>	<i>Max</i>	<i>M</i>	<i>SD</i>	<i>Min</i>	<i>Max</i>	
MCAPIS_DRC													$t = -3.895$
Descriptive Results	34.54	4.98	24.55	49.67	32.36	3.51	24.55	39.55	35.86	5.29	24.78	49.67	df = 115 $p = .000$
	$N = 117$		%		$n = 44$		%		$n = 77$		%		
ICAPIS_DRC													Chi-square
Complexity Index													14.611 $p = .001$
Low	36		30.8		20		45.5		16		21.9		
Medium	60		51.3		23		52.3		37		50.7		Cramer's V
High	21		17.9		1		2.3		20		27.4		.353 $p = .001$

Notes: ICAPIS_DRC has the following cut-off points: 1) Low ≤ 31.22 ; 2) Medium = 31.23 to 38.56; 3) High ≥ 38.56

Source: Authors own elaboration.

4. Discussion

The results show that during the first 6 months of COVID-19 pandemic 117 situations of patients with associated social problems strictly related to the pandemic were reported, of which 62.4% aggravating social situations were already monitored by Social Work. The aggravation of the social situation is more significant when compared to new situations (37.6%), which corroborates the fact that the pandemic has contributed to worsening social and economic difficulties and adding unpredictability in social and family contexts (Magalhães et al. 2020). As mentioned by Redondo-Sama et al. (2020: 1), “social work during the COVID-19 crisis has faced one of the most challenging times to cover urgent social needs in an uncertain scenario”.

Economic deprivation was the most frequent social issue. It should be noted that many patients have no access to state social protection measures due to the suspension of medical appointments, which is a key condition to continue applying for social support measures. The pandemic has restricted some social rights and guarantees (Martins 2020), namely those specific to these patients, which are essential to compensate for their vulnerable medical and social situation.

Unemployment was the second most frequent issue among participants, which stems from precarious work situations or having work activities that suffered strong constraints during the lockdown. Possibly some temporary work situations, with more fragile employment relationships were terminated, leaving these people in a state of greater social and economic vulnerability (Mamede et al. 2020).

Social and family isolation was strongly associated with detachment and confinement. The security measures that implied detachment and self-isolation have negatively affected the relationship among people (Lee et al. 2020; Saladino et al. 2020), namely through separation from loved ones, such as extended family and other members of their support networks. Forced isolation, felt particularly by the risk groups as a feeling of loss of freedom, added to the uncertainty about the progression of the Pandemic lead to feelings of helplessness (Li, Wang 2020). Many chronic kidney disease patients undergoing treatment were forced to stop attending day care centres, which closed due to the pandemic context. As day care centres are an important response and reference network for many, this situation brought multiple negative impacts on the patients' daily lives.

The need for material/instrumental support, focused on financial support, is associated with situations of economic deprivation and unemployment (Olim et al. 2018b), followed by the need for secondary network support, which is mainly met through home support for patients who no longer have day-care centre support. The needs for advocacy and psychosocial intervention were focused on the family, mainly in situations of unemployment, economic deprivation and social isolation. The family in these situations emerges as an important support

resource, which is often the only close support network available (Guadalupe 2012), and this can lead to overloading in a long-term pandemic situation. It should be noted that in a previous study with the same population the two types of social needs were also the most highlighted (Olim et al. 2018a), which seems to occur regardless of the context marked by the Pandemic.

Most situations had an adequate response in the social intervention process (50.4%) although we still have a significant percentage (38.5%) that was awaiting a response, regarding situations of requests for official social protection due to unemployment and economic deprivation. These processes are highly constrained and delayed, thus aggravating the vulnerability of the situations. For example, economic need and unemployment were more frequent among those who were already monitored by Social Work, which aggravated the previous situation.

We found that for most of the social problems (economic deprivation, unemployment and homelessness), the associated needs were for material or instrumental support to ensure the subsistence of the deprived patients.

Social and family isolation was more frequently identified in new referrals to Social Work, a problem that emerged as a consequence of the lockdown that forced many patients to stop having such frequent contact with family, friends and the community (Relvas et al. 2020). A study in Portugal with haemodialysis patients during the COVID-19 outbreak identified several negative psychosocial impacts, as well as impacts on disease and treatment-related health behaviours (Sousa et al. 2021). Among the psychosocial negative impacts that patients revealed, the study pointed out impacts on family relationships with a significant decrease in social contacts with family members with their regular interpersonal interactions (Sousa et al. 2021), reaffirming the relevance of this problem to be addressed with innovative interventions. Furthering knowledge about the effect of COVID-19 on individuals with adverse social determinants, as well as developing innovative approaches are required to ensure effective social monitoring and social protection (Abrams, Szefler 2020).

The results indicate that the situations referred to Social Work with social problems exclusively associated to COVID-19, present, for the most part, a medium complexity in social intervention. In new situations with no evidence of previous social problems, the complexity is mostly low or medium. The situations classified as high complexity are more frequent among patients whose situations deteriorated during the period under analysis, which reveals the special vulnerability of social situations when added to new risk factors. In this regard, Redondo-Sama et al. (2020: 12) underlined the crucial “role of social work to overcome difficulties of vulnerable groups in the context of the COVID-19”.

5. Conclusion

The results show a negative impact of the pandemic on the social situations of chronic renal patients. From a universe of 2627 patients, 117 (4.5%) presented new or aggravated social problems, most of them related to situations of economic deprivation and/or lack of income, unemployment and social isolation. In this critical period, needs for material and instrumental support were identified, as well as needs for support from the secondary network, with most of these needs having been met favourably in the intervention process. We found that the new referrals had moderate or low levels of complexity, while the social situations aggravated by COVID-19 had a higher level of complexity in social intervention, with a very strong evidence of association between the variables ($p < 0.001$).

The size of the sample and the scarcity of publications exploring the impact of the pandemic on this population give this study a particular relevance, both in terms of knowledge and social intervention.

This study is the first step towards a deeper analytical study of these characteristics, allowing the formulation of a set of hypotheses, as well as the correlational exploration with other relevant variables in the treatment and follow-up processes of these patients, namely the study of associations between clinical, social and psychosocial variables, which may represent an important contribution to the systematization of priorities in social intervention with CKD patients.

Our study has some limitations. The sample is non-probabilistic and the data result from social processes, and we did not collect data regarding specific variables related to the experience of the Pandemic and its consequences, which would only be possible through a survey. Future research is needed to verify our findings using pandemic specific questionnaires to evaluate in detail its psychosocial implications. It is fundamental that future studies on at-risk populations focus on psychosocial dimensions, so that we can have evidence to consider new intervention programs and reinforce social protection responses for the especially socially vulnerable population.

“The ways and means by which people are coping with the pandemic would be based on the quality and resilience of their social and psychological framework”, therefore “social policy with respect to COVID-19 also needs to encompass the most vulnerable sections of the population” (Bhattacharya 2020: 9), such as CKD patients who deal with material deprivation and lower income due to job loss, as it is the case among the participants in this study.

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SPOŁECZNY WPLYW PANDEMII COVID-19 NA PACJENTÓW CKD LECZONYCH DIALIZAMI W PORTUGALII

Abstrakt. Celem prezentowanego badania była ocena społecznego wpływu pandemii COVID-19 na pacjentów z przewlekłą chorobą nerek, populację szczególnie narażoną na liczne powikłania w przypadku zarażenia się wirusem SARS-CoV-2. Autorzy skupili się na analizie problemów społecznych, które pojawiły się i nasiliły w pierwszej fazie pandemii. W badaniu wzięło udział 117 pacjentów leczonych w CKD, skierowanych do otrzymania pomocy socjalnej. Zaobserwowano wzrost liczby osób kierowanych do otrzymania pomocy. Nowych zgłoszeń było 37,6%, a 62,4% z nich związane było z pogorszeniem społeczno-ekonomicznej sytuacji pacjenta – głównie deprawacją ekonomiczną lub brakiem dochodów, bezrobociem i izolacją społeczną. Złożoność interwencji socjalnej była wyższa wśród osób z nasilonymi problemami społecznymi. Wyniki otrzymanych badań mają nie tylko walor naukowy, lecz także praktyczny – pozwalają pracownikom socjalnym na planowanie pomocy skoncentrowanej na najistotniejszych problemach pojawiających się w kontekście wyzwań pandemicznych.

Słowa kluczowe: pandemia COVID-19, CKD, hemodializa, potrzeby socjalne, praca socjalna.