Escola Nacional de Saúde Pública

UNIVERSIDADE NOVA DE LISBOA

Assessing the knowledge about kidney chronic disease in Portugal: a population-based study

Curso Mestrado Gestão da Saúde

Ana Filipa Fernandes Lopes Ferreira Alves

Maio 2023

Escola Nacional de Saúde Pública

UNIVERSIDADE NOVA DE LISBOA

Assessing the knowledge about kidney chronic disease in Portugal: a population-based study

Dissertação apresentada para cumprimento dos requisitos necessários à obtenção do grau de Mestre em Gestão da Saúde, realizada sob a orientação científica de Ana Rita Pedro e Joana Alves

Maio 2023

“I learned a lesson I’d never forget. The lesson was that, when you have setbacks and failures, you can’t overreact to them.”

“At various points, in big ways and small, we get knocked down. If we stay down, grit loses. If we get up, grit prevails.”

Angela Duckworth in Grit: The Power of Passion and Perseverance

Agradecimentos

Se em Setembro de 2019 ficaria na dúvida sobre escrever estes agradecimentos, hoje, passados mais de 3 anos, é imprescindível fazê-lo uma vez que este foi sem dúvida um trabalho de grupo.

Foram os melhores e piores anos da minha vida, em que tive de aprender a parar, respirar e ganhar forças para continuar e várias são as pessoas que consciente e/ ou inconsciente me ajudaram a chegar aqui.

À professora doutora Ana Rita e professora doutora Ana Escoval por me terem incentivado/ forçado a parar e desfrutar do melhor momento da minha vida, obrigada nunca será demais, foi dos melhores conselhos da minha vida.

Às minhas orientadoras, professora doutora Ana Rita Pedro e professora doutora Joana Alves por terem respeitado as minhas ausências quando precisei ganhar forças, por todo o tempo e paciência, pelas inúmeras revisões, pelos abonões quando fizeram falta.

Ao Fernando Genovez por toda a disponibilidade, paciência e ajuda com o tratamento estatístico e SPSS.

À Marisa Cavalinhos e Filipa Serra pelas revisões imparciais.

Ao Tai Wai Fong pela revisão de última hora em tempo record, muito obrigada pela disponibilidade e paciência.

À Doutora Isabel Andrade por mais uma vez me ajudar na conclusão de um trabalho, por toda a disponibilidade no esclarecimento de questões de formatação e sugestões de apresentação.

Ao Albano Perdigão e João Pais sem dúvida dois amigos que este curso de mestrado trouxe para a minha vida e que não deixarei fugir. Obrigada pelos desabafos de grupo, palavras de incentivo, revisões, ao longo destes anos fomos nos forçando mutuamente a sempre continuar.

Ao meu bunker pessoal por estarem sempre presentes nos maus momentos para chorarem comigo e me darem forças a continuar e, nos bons para celebrarmos o bom que a vida nos traz. Perto ou longe foram imprescindíveis para este momento...

À Filipa Serra, a prova que a distância não afasta ninguém... obrigada pelas horas ao telefone, por me ouvires, me aconselhares.

À Ana Patinhas, pelas longas conversas por vezes vazias de conteúdo, mas que tanta falta fazem.

À Catarina Rodrigues, a minha menina mulher que tantas vezes me apoiou como tão bem sabe, sem dizer uma palavra.

À Alexandra Rodrigues que mesmo longe esteve sempre lá e sempre deu um olá quando sabia que o barco estava a abanar.

Ao António Patinhas, o meu mano, por estar sempre a meu lado, me ter dado o ombro, o braço (literalmente) e sempre me recordar o melhor de mim e me incentivar a dar sempre mais.

À Vanessa Pinheiro, a minha *bestie* de sempre e para sempre, por me ouvir vezes sem conta e por simplesmente fazer parte da minha vida.

Aos meus pais, que sempre me incentivaram a seguir os meus sonhos e nunca desistir, mesmo ausentes sempre consegui ouvir um “tu consegues!”. A vossa partida foi sem dúvida o golpe baixo destes 3 anos, mas onde quer que estejam sei que sempre vão acreditar em mim, nos meus valores e nas minhas capacidades. Simplesmente adoro-vos!

Ao meu sobrinho, Samuel Ferreira, o meu primeiro coração fora do peito, por se manter sempre ao meu lado, e me ver mais do que como uma tia, mas um exemplo, uma amiga. Faz-me querer ser melhor a cada dia.

Ao meu grande amor, Joaquim Alves, sem ti.... Obrigada por tudo, pela força, pelo apoio nos momentos em que fui abaixo, por teres abdicado dos teus hobbies para eu ter mais tempo, por nunca criticares as minhas ausências por estar no computador, pela fé imensurável nas minhas capacidades, por nunca me teres deixado desistir e por nunca duvidares de mim mesmo quando eu duvidei...

À minha filhota Matilde pelos abraços apertados sempre que fugia do computador, pelo sorriso ao me veres em cada instante e por me ter ensinado a ver tudo com outros olhos.

E por fim, obrigada vida, pelas memórias, lições de vida, obstáculos no caminho, valores apreendidos e pela capacidade em pegar nas coisas relevantes do passado, definir objetivos, traçar um rumo e voar!

Index

Figure Index

Table Index

Abbreviations Index

CKD – Chronic Kidney Disease

DRC – Doença Renal Crónica

ESRD – End Stage Renal Disease

Abstract

Background: Chronic Kidney Disease (CKD) represents a high economic and social burden, being prevention and early detection the main strategies to decrease its burden. Thus, CKD knowledge is essential to persuade the population to adopt favourable health behaviours. This study evaluated the CKD knowledge in a population of non-health professionals in Portugal and explored its socioeconomics determinants.

Methods: A cross sectional survey was conducted at Portugal, online (n=1303) and by telephone (n=384) using the CKD knowledge questionnaire, after its transcultural adaptation. The final sample included 1209 persons. Finally, one-way ANOVA, independent t-tests and a multivariate linear regression were performed to evaluate the CKD knowledge score, and, to explore its socioeconomic determinants.

Results: The mean (SD) knowledge score was 14,30 (± 3,36). Higher scores were found among women, participants with secondary education level or higher, kidney disease history, and with CKD familiar history ($p<0,001$). Individuals with secondary school, graduated and post graduated had more 0,72 ($p=0,02$), 1,21 ($p<0,001$) and 0,71 ($p=0,048$) points on CKD knowledge than those with elementary school level. Also, women, respondents with kidney disease history and CCKD familiar history had, respectively, more 0,71($p=0,002$), 1,42 ($p<0,001$) and 1,34 ($p<0,001$) CKD knowledge score points.

Conclusion: CKD Knowledge in Portugal was relatively low; from a score of 24 points, half of the sample had a knowledge score lower than 14 points. Improving CKD knowledge of people with education level lower than secondary school may influence its prevention and early detection, and consequently its global burden.

Keywords: Chronic Kidney disease, Cross-sectional study, Knowledge, Determinants

Resumo

Introdução: A Doença Renal Crónica (DRC) representa uma elevada carga económica e social, sendo a sua prevenção e deteção precoce as principais estratégias para diminuir essa carga. Assim, o conhecimento em DRC é essencial para persuadir a população a adotar comportamentos favoráveis à sua saúde. Este estudo avaliou o conhecimento em DRC numa população de não profissionais de saúde em Portugal e explorou os seus determinantes socioeconómicos.

Métodos: Foi realizado um inquérito transversal em Portugal, online (n=1303) e por telefone (n=384) utilizando o questionário de conhecimento em CKD, após a sua adaptação transcultural. A amostra final incluiu 1209 pessoas. Por fim, foram realizados testes one-way ANOVA, testes t independentes e uma regressão linear multivariada para avaliar a pontuação de conhecimento em DRC e explorar os seus determinantes socioeconómicos.

Resultados: A pontuação média (DP) de conhecimento em DRC foi de 14,30 ($\pm$ 3,36). Pontuações mais elevadas foram encontradas em mulheres, participantes com ensino secundário ou níveis mais elevados, com história de doença renal e com história familiar de DRC ($p<0,001$). Indivíduos com ensino secundário, superior e pós-graduado tiveram mais 0,72 ($p=0,02$), 1,21 ($p<0,001$) e 0,71 ($p=0,048$) pontos no conhecimento em DRC do que aqueles com ensino básico. Além disso, mulheres, indivíduos com história de doença renal e indivíduos com história familiar de DRC tiveram, respetivamente, mais 0,71($p=0,002$), 1,42 ($p<0,001$) e 1,34 ($p<0,001$) pontos de conhecimento em DRC.

Conclusão: O conhecimento em DRC em Portugal é relativamente baixo; de uma pontuação de 24 pontos, metade da amostra teve uma pontuação de conhecimento inferior a 14 pontos. Melhorar o conhecimento em DRC em pessoas com nível de escolaridade inferior ao ensino secundário pode influenciar sua prevenção e deteção precoce e, consequentemente, sua carga global.

Palavras-chave: Doença renal crónica, Estudo transversal, Conhecimento, Determinantes

Introduction

Chronic diseases are a major healthcare challenge for many countries, Chronic Kidney Disease (CKD), in particular, defined as a reduced glomerular filtration rate, increased urinary albumin excretion, or both, is an increasing public health issue (1). Additionally the growing number of patients expected to progress to End Stage Renal Disease (ESRD) and subsequently requiring dialysis or kidney transplant further exacerbates the health-related issues faced (2,3).

CKD is a silent disease which results on late diagnosis and increased chances of adverse effects (4), resulting on high number of ESRD patients who require more expensive treatments (1–3,5–8). So, focusing on early detection, slowing disease progression and disease prevention are essential to decrease CKD global burden (2–4,9).

Since health behaviors impact kidney disease management ,CKD major risk factors are influenced by lifestyle and environmental factors (10). Previously identified risk factors and/ or predictors to CKD are: age (11–13), being male (14), area of residence (12), marital status (11,15), occupation (12,16), recent renal function assessment (12), CKD familiar history (15,17), personal history of kidney disease (15), non-white, diabetes, obesity, hypertension, and/or cardiovascular disease (1,2,7,9), and low education level (1,4–6,11,12,15,16,18,19) or income (1,11,16).

It is a topic of major relevance, as CKD affects more than 10% of the general population worldwide, more than 800 million individuals, it is has emerged as one of the leading causes of mortality, exhibiting a notable increase in associated deaths over the last two decades (20). Mortality rates ascended to 20% in kidney transplant recipients and to 21% in patients on dialysis (21). Also, 58% of hospitalized covid-19 patients reported acute kidney injury (22), which in time progress to CKD, resulting in an increase of the overall CKD burden (23).

According to the Portuguese Nephrology Association (24), in 2021 Portugal was the country with the highest incidence of dialysis patients and the 8th country in the world with the worst results of incidence, prevalence and progression to ESRD. Also, 60% of diagnosed CKD patients are on haemodialysis and 35% have received a renal transplant, costing ~~of~~ 2-6% of the global health budget related to CKD treatment (25).

Besides the large economic burden on patients, the health care system and the society, CKD is also responsible of premature morbidity and mortality and reduced quality of life (3,8,9). CKD is associated with increased all-cause and cardiovascular mortality, kidney disease progression, acute kidney injury, diabetes, cognitive decline, anemia, mineral

and bone disorders, and fractures (1,2,9). Effects at the psychosocial level are also relevant as CKD has a high impact on the quality of life as patients with ESRD on dialysis are dependent on a machine unless a transplant is done. Additionally, these patients have a higher absenteeism due to symptoms and because of the need for hemodialysis, which might also be disruptive for their families.

Increased knowledge and awareness on CKD and kidney disease have been shown on previous studies to prevent CKD, to impact the effectiveness of CKD management and consequently, to reduce significantly economic and public health burden. Knowledge of CKD and its risk factors increase the perception of being at risk, which in turn increase health seeking behavior (1,3,7,10,26) and information seeking (5), leading to better outcomes (1,3,5,7,10,17,26–33) such as, to prevent CKD, avoid/slow its progression and reduce CKD associated mortality (5,7,17,26,34).

Previous data suggests, to reduce CKD global burden it is urgent to identify CKD patients early; to develop awareness and educational programs heading general population, providers and patients, both to prevent CKD and its associated diseases (13), and to increase awareness of CKD, its risk factors and opportunities for screening (9), as recommended by European Kidney Health Alliance (23).That said, strategies to reduce burden and costs related to CKD need to be included in national programs for non-communicable diseases as population-based preventive strategies appears to be the most cost-effective and the best solution to CKD management (1,7,10,35).

As pointed out in the literature, one of the obstacles to the success of prevention programs is the lack of knowledge/awareness about the disease by the public (15). A better understanding of CKD's burden at the global level is of utmost relevance, but to do so, it is crucial to evaluate the actual CKD's knowledge and to explore its socioeconomics determinants.

According to literature regarding CKD knowledge, it is usually evaluated through questionnaires, such as: a validated self-report 73-item questionnaire comprising 4 sections, participants demography and medical history, knowledge about CKD, awareness of CKD risk factors and, awareness of CKD complications (36); a validated CKD awareness questionnaire with four dimensions, diet, exercise, laboratory examinations, and medical resources (37); a validated 20-questions questionnaire (3); the CKD knowledge questionnaire (15); a validated questionnaire to assess the knowledge of the respondents on the general function of the kidneys, causes and symptoms of chronic kidney disease, and management and treatment of kidney disease (38); and others (7).

For the purpose of this survey, The CKD Knowledge Questionnaire was chosen as it is a short and well formulated about population CKD general knowledge. This questionnaire comprises five dimensions, general aspects, kidney functions, kidney analysis, risk factors, and signs and symptoms, and evaluates CKD knowledge score (15). This questionnaire was developed, validated, and applied in Australia and a transcultural adaptation was performed to apply it in Portugal (Additional file 1). Results from the CKD knowledge questionnaire in Australia showed a significant association of CKD knowledge with age (older), occupation, annual income, higher education level, family history of kidney failure, personal history of hypertension, diabetes, heart disease and stroke, and currently or previously living in a relationship (15). Association of CKD knowledge with annual income was later excluded as those who refused to answer to annual income had a significant lower CKD knowledge score.

The CKD knowledge questionnaire (15) allows the evaluation of the CKD knowledge score as well as to explore its relation with other factors so, a cross sectional study was performed to be the first step of a strategy to reduce CKD global burden by (i) evaluating the knowledge of general population about CKD in Portugal; and (ii) by exploring the influence of socioeconomics determinants on CKD knowledge in a population of non-health professionals with CKD in Portugal. As far as we know this is the first research regarding CKD knowledge in Portugal.

With the aim to reduce the global burden of CKD, this study is aligned with the sustainable development through achieving a better health (39) by providing crucial information to define prevention strategies and health programs aiming to achieve CKD prevention, early detection and slower disease progression.

Health, is an outcome, a determinant and an enabler to sustainable development goal (40) and the management of CKD is essential to a sustainable development due to its high prevalence and increasing global burden, as it affects 1 in 10 people. CKD is a cause of low quality of life, absenteeism, high morbidity, and a burden to the economy, healthcare system and society.

The Portuguese “2021-2030 National Health plan” (41) was based on “The 2030 Agenda for sustainable development” (39), a comprehensive CKD strategy should have been included: a national program for CKD’s early detection, to increase general public and providers CKD knowledge and a better management of patients to slow CKD’s progression. This study aims to add substantial evidence concerning CKD, in particular, about CKD knowledge actual level and exploration of its socioeconomic determinants which can be used as a baseline to the mentioned programs.

Providing an initial diagnosis of CKD knowledge and exploring its determinants this study is the base to further interventions concerning CKD management which consequently result in decreased burden to the healthcare and economic system and to the society. Summarizing, due to its high burden, an effective CKD management has a substantial impact on the healthcare management which makes this topic to relevant to this field of study.

This study is included in a major study in collaboration with AstraZeneca regarding the study of CKD knowledge in Portugal. Also, this thesis is going to be submitted to BMC Public Health as an article.

Article

Assessing the knowledge about Kidney Chronic Disease in Portugal: a population-based study

Ana Alves[1], Joana Alves[2], Fernando G. Avelar[1], Beatriz Raposo [1], João Couceiro[3], Susana Henriques[3], Hugo Martinho[3], Ana Rita Pedro[2]

[1]NOVA National School of Public Health, Public Health Research Center, Universidade NOVA de Lisboa, Lisboa, Portugal

[2]NOVA National School of Public Health, Public Health Research Centre, Comprehensive Health Research Center, CHRC, NOVA University Lisbon, Lisbon, Portugal

[3]Astrazeneca, Lisbon, Portugal

Background

Chronic Kidney Disease (CKD) is defined as “abnormalities of kidney structure or function, present for >3 months, with implications for health” (41), being those measured by estimated glomerular filtration rate (eGFR) < 60 mL/min/1.73 m2 or presence of albuminuria higher than 30 mg/g for more than 3 months. Kidney Disease Improving Global Outcomes (KDIGO) organization defined 5 stages of CKD dysfunction, according to estimated glomerular filtration rate (eGFR) and albuminuria (41). CKD affects 10% of the world population (20), and it is expected to increase in the next years. This has severe consequences to the global burden of the disease, and threatens the sustainability of the health systems (1–3,5–8). Additionally, the population with CKD and End-Stage Renal Disease (ESRD) usually carry a substantial burden of other medical conditions such as cardiovascular disease, diabetes, and stoke, which worsens the disease burden/cost (1,2,9).

Recent data shows a prevalence of 20.9% (95% CI: 6.5–35.3%) of CKD among primary care users in Portugal, with 0,1% prevalence of stage 5 CKD (13). At this advanced stage the kidneys are at failure or close, being the dialysis or kidney transplantation are presented as the only options available (42), resulting on a cost of at least 2 to 6% of the budget to health care (25). Also, its prevalence is expected to increase until 2040 to the 5th main cause of years lost due to disease in Portugal (26,43).

Knowledge of CKD and of its risk factors improves risk perception, and, therefore, improves self-management of the disease and increases the like hood of healthier

behaviour and of seeking for adequate and appropriate care resulting on better clinical outcomes and increased quality of life (5,7,33,10,26–32).

Knowledge of CKD can be defined as the “ability to provide a correct definition for CKD or correctly naming risk factors, symptoms, and diagnostic tests for CKD” (5). Also, CKD knowledge contribute to CKD awareness as it includes both general knowledge of CKD, its risk factors, causes, appropriate treatment and consequences, and knowledge of individual risk and CKD status (5,17,34). Awareness of CKD status depends on understanding individual risk, which depends on CKD general knowledge (5). That said, the terms “awareness” and “knowledge” are used interchangeably throughout (5).

However, despite being recognized as an important public health issue, few studies are available on this field with evidence showing that CKD knowledge and awareness among patients and providers is usually low (1,7). This is quite worrisome since people with more knowledge about CKD and its risk factors adopt healthier behaviours, and are more likely to modify their lifestyle (1,3,7,10), which has the potential to prevent CKD or avoid its complications. This fact is particularly relevant in high-risk individuals, like hypertensive or people with type 2 diabetes in which the early stages of the disease are silent with low symptomatology but with high risk of progression. (11) Some studies have proven that improving patient knowledge is linked with higher rates of pre-dialysis nephrologist care, peritoneal dialysis, pre-emptive transplant wait listing, transplantation (44), increased time to commencement of renal replacement therapy (34) and better clinical outcomes among people with CKD (5,17,34) as those with higher perceived risk of CKD frequently seek for information, ask the doctor about CKD and get tested (5). Also a better lifestyle and healthier behaviours, such as optimizing of nutrition, increasing physical activity, quitting smoking or using timely and adequate medicines, has the potential to slow disease progression and reduce CKD associated mortality (7,26).

Some determinants/ predictors of CKD knowledge have been identified, such as education (5,28,30,31,33–35), age (11,12), sex (male) (14), area of residence (12), marital status (11,15), annual household income (11,16), occupation (12,16), recent renal function assessment (12), CKD familiar history (15,17) and self-reported history of kidney disease (15). The studies mentioned show a significant higher CKD knowledge with each of the stated conditions and/or higher levels of it. Regarding occupation, opposite results were found, one study revelled higher CKD knowledge among unemployed (16), while other showed higher CKD knowledge on healthcare professionals and students versus unemployed (12)

Thus, it is essential to understand the dimension of CKD knowledge and explore its determinants, whether demographic, socioeconomic, healthcare and/or clinical (5). Chronic Kidney Disease Knowledge Questionnaire is commonly used for evaluating population CKD knowledge, and to explore associated factors (15). Given the limited existing information on CKD knowledge, particularly in Portugal, this study aims to, (i) to evaluate the knowledge of general population about CKD in Portugal; and (ii) explore the influence of socioeconomics determinants on CKD knowledge in a population of non-healthcare professionals.

Methods

Study design

A cross-sectional study was performed, using The Chronic Kidney Disease Knowledge Questionnaire adapted for portuguese version, to evaluate the knowledge of general population about CKD in Portugal and to determine the socioeconomic determinants of CKD Knowledge in a population of non-healthcare professionals with CKD in Portugal. The questionnaire was applied online and by telephone between the 25th of January 2022 and 11th February 2022. Respondents were invited to participate through existing contacts and mailing lists, social networks, social media and through collaboration with patient associations, municipalities, and groups of healthcare professionals.

Survey questionnaire

The Chronic Kidney Disease Knowledge Questionnaire was adapted from Gheewala et al. (15) and a transcultural adaptation was done, as follows: (i) the questionnaire was translated to Portuguese by two bilingual interpreters; (2) it was verified by the researcher; (3) a final version was confronted with the original one; and, (4) a pre-test was performed.

The questionnaire (additional file 1) is composed of 24 closed answers (true, false, do not know), and was structured into 5 sections investigating the following: general aspects, kidney function, kidney analysis, risk factors, signs and symptoms and CKD consequences.

The outcome variable was CKD knowledge score (SCORE 24), a numeric continuous variable, resulting from the correct answers (1 point each) to the questionnaire. It reflects the awareness of CKD (15).

Additionally, it was included a section of sociodemographic and health characterization with closed and open questions: age, gender, geographic location, marital status, number of co-habitants, maximum education level, monthly wage, occupation, diseases,

stroke, kidney disease history, CKD familiar history, access to health care, relation with health personnel and number of visits to healthcare services.

This study focused on the socioeconomic factors age, gender, education, wage and geographic location and, on relation with healthcare personnel, self-reported kidney disease history and CKD familiar history as these last three could act as potential confounders. All independent variables in study were coded as categorical variables. The age was grouped in 3 categories: 18 to 39 years, 40 to 59 years, and more than 60 years old. The variable for net wage was grouped in five categories (less than 705€, 706-1410€, 1411-2115€, 2116-2820€ and more than 2821€), to avoid a low number of cases in some of the categories.

The study group

An initial sample of 1687 people was obtained after applying the questionnaire online (n=1303) and through telephone interviews (n=384). As the respondents invited had a high probability of being related to healthcare, being healthcare professional was defined has an exclusion criteria, resulting on a final sample of 1209 individuals. Healthcare professionals were excluded to reduce the potential bias introduced by the fact that they would have more experience regarding CKD, which could overestimate the CKD knowledge score results. However, a total of 478 excluded healthcare professionals were used for the consistency analyses.

Data analysis

Cronbach's alpha was used to measure the questionnaire's reliability. The continuous variable normality was tested using Shapiro-Wilk test. Finally, Mann-Whitney U tests were performed to test for significant differences between laypeople ang health professionals' groups.

Firstly, a descriptive analysis was performed. Then, considering the variables characteristics, a one-way ANOVA was performed to evaluate the association of CKD knowledge score with age, education, wage, geographic location, and relation with health personnel. Independent t-tests were performed to evaluate gender, kidney disease history and CKD familiar history differences on CKD knowledge score. And Eta-squared was also determined for all significant variables ($p<0,05$).

Additionally, a multivariate linear regression was performed for the variables that shown statistically significant association ($p<0,05$) with CKD knowledge score in the bivariate analysis.

Results

CKD questionnaire consistency

The Cronbach's alpha of 0,84 was obtained, indicating a good internal consistency. The hypothesis of normality was rejected. Mann-Whitney U tests were performed showing that there is a statistically significant difference between laypeople and healthcare professionals' /health students' groups ($p<0,05$).

Descriptive analysis

Table 1 presents the characteristics of the sample. Approximately 75% of the respondents were females, and almost 50% had ages between 40-59 years old. The respondents were mainly from the north of Portugal (26,9%), central region (20,6%) and Lisbon metropolitan area (39,9%). Regarding education level, 39,9% of the respondents had finished graduate level, 29,9% had finished secondary school, 16,1% had the post-graduate level, and 14,5% had the elementary school. Most of the respondents received a wage between 706 and 2115 euros, while 32,5% received between 706 and 1410 euros, and 28% received between 1411 and 2115 euros. Regarding the reported relation with healthcare system, 60,7% of the respondents referred having a good relation. More than 80% of the respondents have CKD familiar history or self-reported kidney disease history.

Table 1- Descriptive analysis of the study sample

Characteristics	Categories	N	n	%
Age (Years)	18 - 39	1209	299	24,7
	40 - 59		573	47,4
	60 +		337	27,9
Gender	Male	1203	312	25,9
	Female		891	74,1
Georgraphic location	North	1199	323	26,9
	Central region		247	20,6
	Lisbon Metropolitan area		478	39,9
	Alentejo		71	5,9
	Algarve		38	3,2
	Autonomous regions		42	3,5
Education	Elementary school	1189	172	14,5
	Secundary school		355	29,9
	Graduate		470	39,5
	Post Gaduate		192	16,1
Wage (euros)	-705	832	82	9,9
	706 - 1410		270	32,5
	1411 - 2115		233	28,0
	2116 - 2820		115	13,8
	2821 +		132	15,9
Relation with health personnel	Really bad/ bad	1122	40	3,6
	Intermediate		225	20,1
	Good		681	60,7
	Excellent		176	15,7
CKD familiar history	No	1152	939	81,5
	Yes		213	18,5
Kidney disease history	No	1159	985	85,0
	Yes		174	15,0

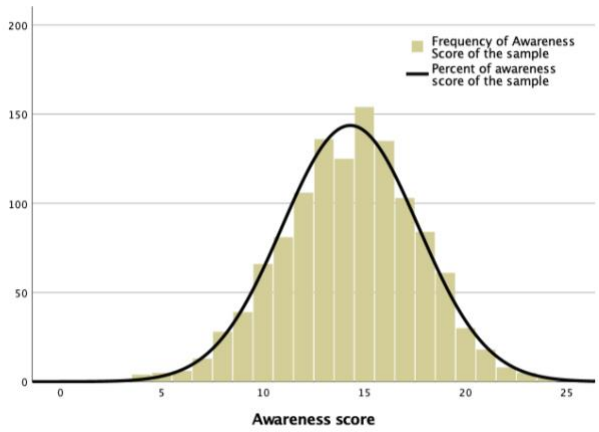

Figure 1 - Distribution of the chronic kidney disease knowledge score of the study sample

The mean knowledge score of the sample was 14,30 (standard deviation, SD= 3,36), with values ranging from 4 to 24 points (additional file 1). Half of the sample had a knowledge score of less than 14 points, as shown of *Figure 1*.

Results of the bivariate analysis performed using one-way ANOVA and independent t-tests, presented at *table 2* and *table 3*, as described before, showed a significant association between education levels and CKD knowledge score (p<0,001), an higher CKD knowledge score among women (p<0,001), and on people with CKD familiar history or self-reported kidney disease history (p<0,001). Also, Turkey test, used as a post hoc test, proved that there is no significant difference on CKD knowledge scores between secondary school, superior school, and higher degrees groups. However, either of those tree groups show a higher CKD knowledge score when compared with the group till 3rd cycle (p<0,001). Accordingly to Cohen (1988) (45), Eta squared shows a medium effect of education on CKD knowledge, a smaller effect of gender and a large effect of CKD familiar history and self-reported kidney disease history on CKD knowledge, being CKD familiar history the major influencer.

No significant relation was found between CKD knowledge and age, geographic location, wage, or according with the type of relation with health personnel.

Table 2-Results of the bivariate analysis using one-way ANOVA

Characteristics	Categories	Socre (mean+DP)	df(a)	F	p-value	Eta-squared (b)	Comparison Post-hoc (c)
Age (Years)	18 - 39	14,19 ±3,555	2, 1206	0,244	0,783	NA	NA
	40 - 59	14,32 ±3,395					
	60 +	14,38 + 3,109					
	Total	14,30 ± 3,357					
Georgraphic location	North	14,38 ± 3,284	5, 1193	0,161	0,977	NA	NA
	Central region	14,35 ± 3,313					
	Lisbon Metropolitan area	14,24 ±3,349					
	Alentejo	14,42 ± 3,698					
	Algarve	14,08 ± 2,954					
	Autonomous regions	14,07 ± 3,96					
	Total	14,30 ±3,351					
Education	Elementary school	13,38 ±2,970	3, 1185	5,76	**<0,001**	0,014	Secundary school, graduate and post graduate levels have a statistically significant difference from elementary school level. No statistically significant differences between CKD awareness of secundary school, graduate and post graduate levels.
	Secundary school	14,30 ±3,348					
	Graduate	14,63 ±3,447					
	Post Graduate	14,30 ± 3,446					
	Total	14,30 ± 3,372					
Wage (euros)	-705	14,27 ± 3,403	4, 827	0,741	0,564	NA	NA
	706 - 1410	14,29 ± 3,221					
	1411 - 2115	14,46 ±3,712					
	2116 - 2820	14,42 ± 3,482					
	2821 +	14,88 ± 3,162					
	Total	14,45 ± 3,408					
Relation with health personnel	Really bad/ bad	14,35 ±3,309	3, 1118	0,849	0,467	NA	NA
	Intermediate	14,34 ± 3,328					
	Good	14,25 ±3,328					
	Excellent	14,70 ± 3,401					
	Total	14,35 ±3,338					

(a) df values

(b) Cohen classifies Eta-squared velue of 0,001 as a small effect, 0,06 as a medium effect and 0,14 as a large effect

(c) Turkey post hoc comparison (p < 0,05)

Table 3 - Results of the bivariate analysis using independent t-tests

Characteristics	Categories	Socre (mean+DP)	t	df	p-value	Eta-square (a)
Gender	Male*	13,69 ± 3,439				
	Female	14,51 ± 3,306				
	Total	14,30 ± 3,359	-3,748	1201	**<0,001**	0,012
CKD familiar history	No*	14,09 ± 3,362				
	Yes	15,65 ± 2,965				
	Total	14,38 ± 3,346	-6,273	1150	**<0,001**	0,033
Kidney disease history	No*	14,16 ± 3,326				
	Yes	15,45 ± 3,282				
	Total	14,36 ± 3,350	-4,728	1157	**<0,001**	0,019
(a) Cohen classifies Eta-squared velue of 0,001 as a small effect, 0,06 as a medium effect and 0,14 as a large effect						

Multivariate analysis

Table 4 presents the results for the multivariate linear regression. The respondents with post graduate level had more 0,71 points in CKD knowledge score than those from elementary school group (p=0,048). Yet, the biggest diference in the score comes from the graduated group, followed by secundary school (more 1,12 points in CKD knowledge score (p<0,001) and more 0,72 points (p<0,02), respectively). When comparing by sex, women have more 0,71 points on CKD knowledge score than men (p=0,002). Respondents with self-reported kidney disease history and CKD familiar history have higher CKD knowledge score (p<0,001); more 1,42 points and 1,34 points, respectively.

Table 4 - multivariate linear regression for the CKD knowledge score

		B	Std. Error	95% Confidence Interval	P value (Sig.)
	(Intercept)	12,656	0,2857	[12,096-13,216]	0
Gender	Female	0,713	0,2271	[0,268-1,158]	0,002
	Male (a)				
Education	Post graduate	0,71	0,3593	[0,006-1,414]	0,048
	Graduate	1,121	0,303	[0,527-1,715]	<,001
	Secundary school	0,718	0,3097	[0,111-1.325]	0,02
	Elementary school (a)				
Kidney disease history	Yes	1,415	0,2802	[0,866-1,964]	<,001
	No (a)				
CKD familiar history	Yes	1,342	0,2552	[0,842-1,842]	<,001
	No (a)				

Legend: R2=0,08; (a) reference category

Discussion

Main findings

This study showed that CKD knowledge in Portugal was relatively low. In the CKD knowledge score, measured in a scale of 0 to 24 points, half of the respondents scored below 14. Also, the average score was 14,30 (±3,36) and the mean percentage of correct answers was 59,60% (± 13,99). Higher scores were found among women, participants with secondary education level or higher, self-reported kidney disease history, and with

CKD familiar history (p<0,001). The other variables tested, such as age, wage, geographic location, and relation with healthcare personnel, had no significant relation with CKD knowledge.

What is already known on the topic

A similar study was performed in Australia using, as well, a sample of general population, with a bias of higher proportion of people with higher education levels, The characteristics of the sample were quite different from ours, 51,2% of respondents were female, and more than 40% had 50 or more years old. Regarding education, 36,6% had a diploma, followed by 31,7% with a high degree or post graduate diploma, 18,9% completed highest level of school and 12,8% did not complete highest level of school. The survey was performed using The CKD knowledge questionnaire and values of CKD knowledge score from 0 to 22 were obtained and a mean of 10,34 (+5,0), with 50% of population with a CKD knowledge score of 11, values slightly lower than the ones obtained in Portugal. In this study the bivariate analysis shows a significant association between CKD knowledge scores and age, education, occupation, annual income, marital status, personal history of hypertension, diabetes, heart disease and stroke and family history of kidney failure, being annual income later excluded as those who refused to answer and a significant lower CKD knowledge score. In the study performed in Portugal no significant association was found with age and wage, and, as we aim to explore the influence of socioeconomic determinants, the variables occupation, marital status and personal history of hypertension, diabetes, heart disease and stroke will be analysed on further studies. Also, in Australia, a multiple linear regression was performed to predict CKD knowledge score based on age, education, occupation, marital status, personal history of hypertension, diabetes, heart disease and stroke and family history of kidney failure, showing that the variables included were responsible for 10% of CKD knowledge score, a small value as the one obtained in our study using the variables sex, education, kidney disease history and CKD familiar history suggesting the association of other factors not identified.

The results from this study showed that respondents with highest schooling levels, either secondary school, graduated or post graduated, had more points on CKD knowledge than those with elementary school level (respectively 0,72 (p=0,02), 1,21 (p<0,001) and 0,71 (p=0,048)). Although with different methods or samples, previous studies confirm that CKD knowledge has a significant relation with higher levels of education (5,28,30,31,33–35), which can be explained by the fact that highly educated populations are reportedly more knowledgeable about various medical and non-medical conditions (12). One study states that it makes sense since the higher the level of education, the

more knowledge a person will have, but it is stressed that it may not be seen in attitudes and practice (16), while other says that people who had low educational levels had poor knowledge about kidney diseases and poor attitudes toward disease prevention and progression (19). All other mentioned studies justify this association with the fact that it is consistent with literature. However, one study could not find a significant relation between education and CKD awareness (14), but this study was conducted only with people with CKD stage 1-4 and the method for evaluating awareness consisted only on an yes or no question " Have you ever been told you have weak or failing kidneys?, which is quite different from want was done in the present study.

Regarding sex, women had more 0,71 points (p=0,002) in CKD knowledge score than male. From the literature, only one study proved the opposite (14), however that study was taken only on stage 3 CKD patients, used a different method and the sample had an higher proportion of male. That said, the significant association with a specific gender may be related to its proportion on the sample, as our sample has an higher proportion of female, The majority of studies, including Gheewala et al(2018), did not found any association between sex and CKD knowledge (6,15) having in common the fact that the samples had similar proportion of male and female, reinforcing the theory that proportions of gender may influence statistically significant association with CKD Knowledge.

Respondents with self-reported kidney disease history and CKD familiar history had higher CKD knowledge scores (more 1,42 points (p<0,001) and 1,34 points (p<0,001), respectively). This association was previously found in other study (15). This shows the importance of antecedents on the CKD knowledge score. The observation of the relatives and their relationship with the disease might provide an explanation for this. As they may be more familiar with the disease, they could have an increased ability to adopt preventive behaviours, detect symptoms, and manage the disease themselves. The disease burden in later stages and its impact in the family and in the individual with advanced CKD, present a physical, psychological and social damaged that raise the awareness for the disease and the wiliness to prevent in in the future (46).

Regarding age, no significant association was found, although other studies showed a significant association of CKD Knowledge and age. Some studies showed that CKD knowledge increases with age (12,15) explaining that maturity and more years of life experience could be behind this association and that older patients may also be more concerned about their health (12) and also we should consider that in higher ages groups the probability of having CKD is higher (11). However, others show a negative

association of CKD knowledge and age (6,11) but those were applied to CKD patients, while studies with positive or no association were applied to general population.

All the other variables tested had no significant relation with CKD knowledge. This was also observed in the study from Gheewala et al. (2018),the authors found no significant association between CKD knowledge score and wage, geographic location, and relation with health personnel.

Limitations of this study

This study has some limitations. The fact that all healthcare professionals were excluded from our study may result in a bias. However, including them might result in a higher bias since they were overrepresented in our sample. Also, this study showed that the variables included in the model only explained 8% of CKD knowledge score, suggesting that other factors not inclued may be associated such as marital status, occupation, healthcare acess and personal history of hypertension, diabetes, heart disease and stroke. Future studies might investigate the role of other factors.

The sampling was done by convenience regarding existing contacts and mailing lists, social networks, social media and through collaboration with patient associations, municipalities, and groups of healthcare professionals which may represents individuals that are more interested in content related with healthcare are more likely to participate in online channels.

Also, the fact that our sample had a high proportion living on Lisbon metropolitan area (39,9%); only 14,5% respondents with elementary school level, being graduted level the higher proportion with 39,5%, and more than 80% had CKD familiar history and kidney disease history may result on a bias.

Another limitation may be the use of self-resported variables resulting on interpretation errors and/or answer according to what is socially aceptable.

And, finally, this instrument was not yet validated in Portugal as its validation is still in progress by this working group to be published later.

Despite these limitations, this is the first study to evaluate the knowledge of general population about CKD in Portugal and one of the first studies to collect this information for a chronic condition.

Implications

According to previous studies, the most effective strategy for reducing the global burden of CKD is prevention, early detection, improved self-management and decision making skills (7,47), which could prevent CKD and slow its progression.

The literature highlights the role of education and knowledge in achieving these goals (7,47), making it essential to take action to improve education and knowledge among both patients and healthcare providers. However, the results from this study showed that the CKD knowledge in Portugal is somewhat low. Thus, it is of higher priority to improve public knowledge about CKD and address its risk factors (5,7,10,13).

Population-based prevention strategies are considered the most effective solutions for reducing the burden and costs associated with CKD (1,10). These strategies might be integrated into national programs for non-communicable diseases. In Portugal, the Nephrology Portuguese Society expressed concern over CKD not being given enough attention as a healthcare objective in the National Health Plan (2021-2030) (26), Given that CKD affects one out of ten individuals and its incidence has been increasing, the Society proposes to include it in the area of early identification, referral criteria for nephrology consultations, nephroprotection interventions and prognostic-modifying treatment in the National Health Plan (26).

Also, literature shows that places where management strategies were implemented the incidence of ESRD has been reduced (1,10) and Portugal was the first country to develop a management program of CKD in all country with a model of coordinated and integrated care, as Portugal has one of the highest incidence rates and prevalence of stage 5 CKD mostly in dialysis (43). It resulted in progressively costs control, diminished mortality and hospitalization rate among haemodialysis patients, maintaining healthcare provision and treatment quality and patient safety (43).

It is also relevant to notice that any level above elementary school results on a significant difference on CKD knowledge score, so strategies should be implemented to increase education levels at least to secondary school levels, even though the highest difference found was between graduated and elementary school levels, more 1,21 versus more 0,72 (secondary school) points CKD knowledge score.

The relevance of improving CKD knowledge was largely emphasized, but a more extensive analysis in crucial to define effective measures to increase CKD knowledge aiming to obtain better health outcomes, as Portugal is the European country with the highest incidence of patients on dialysis (24).

Considering the fact that CKD is a progressive disease with a long initial asymptomatic evolution, is key to ensure the high risk population is fully aware of the disease and its impact, since the opportunity window is several times lost due to late diagnosis. The diagnose in early stages could present the biggest change in a patient long term prognosis (48).

Summarising, higher education level, better communication, strategies included in national programs and management strategies are some of the paths to reduce CKD global burden.

Conclusions

The CKD knowledge questionnaire was adapted for Portugal and allowed to give a general picture of CKD knowledge in Portugal. Results for CKD knowledge were low, with less than 50% of correct answers on kidney function topic. This is particularly important since, according to available data, CKD prevalence is high in Portugal, with the country ranking 8th worst in the world and the worst in Europe in terms of CKD rates (24). Improving CKD knowledge may influence its prevention and early detection, and consequently its global burden. Thus, future studies should focus on the understanding how to improve the CKD knowledge, through cost-effective interventions.

References

1. Jha V, Garcia-Garcia G, Iseki K, Li Z, Naicker S, Plattner B, et al. Chronic kidney disease: Global dimension and perspectives. Lancet [Internet]. 2013;382(9888):260–72. Available from: http://dx.doi.org/10.1016/S0140-6736(13)60687-X
2. Collins AJ, Gilbertson DT, Snyder JJ, Chen SC, Foley RN. Chronic kidney disease awareness, screening and prevention: Rationale for the design of a public education program. Nephrology. 2010;15(SUPPL. 2):37–42.
3. Peng S, He J, Huang J, Tan J, Liu M, Liu X, et al. A chronic kidney disease patient awareness questionnaire: Development and validation. PLoS One. 2019;14(5):1–13.
4. Nahlah Fahad A, Ahmed Alkhateeb A, Rabah Alsharari A, Naif Alharbi A, Abdullaziz Hamed A. Measuring the Awareness of Chronic Kidney Disease (CKD) with Environmental Evaluation among Adult Diabetic Patients in Hail Region, Saudi Arabia. J Environ Public Health. 2022;2022.
5. Plantinga LC, Tuot DS, Powe NR. Awareness of Chronic Kidney Disease Among Patients and Providers. Adv Chronic Kidney Dis. 2010;17(3):225–36.
6. Wright JA, Wallston KA, Elasy TA, Ikizler TA, Cavanaugh KL. Development and results of a kidney disease knowledge survey given to patients with CKD. Am J Kidney Dis. 2011;57(3):387–95.
7. Roomizadeh P, Taheri D, Abedini A, Mortazavi M, Larry M, Mehdikhani B, et al. Limited knowledge of chronic kidney disease and its main risk factors among Iranian community: An appeal for promoting national public health education programs. Int J Heal Policy Manag. 2014;2(4):161–6.
8. Kumela Goro K, Desalegn Wolide A, Kerga Dibaba F, Gashe Fufa F, Wakjira Garedow A, Edilu Tufa B, et al. Patient Awareness, Prevalence, and Risk Factors of Chronic Kidney Disease among Diabetes Mellitus and Hypertensive Patients at Jimma University Medical Center, Ethiopia. Biomed Res Int. 2019;2019.
9. Schoolwerth AC, Engelgau MM, Hostetter TH, Rufo KH, Chianchiano D, Mcclellan WM, et al. Chronic Kidney Disease: A Public Health Problem That Needs a Public Health Action Plan. Clin J Am Soc Nephrol. 2006;3(2).
10. Oluyombo R, Ayodele OE, Akinwusi PO, Okunola OO, Gbadegesin BA, Soje M,

et al. Awareness, knowledge and perception of chronic kidney disease in a rural community of South-West Nigeria. Niger J Clin Pract. 2016;19(2):161–9.

11. Wembenyui FC. Examining Knowledge and Selfmanagement of Chronic Kidney Disease in a Primary Health Care Setting: Validation of Two Instruments. 2017;(September):157–74.

12. Younes S, Mourad N, Safwan J, Dabbous M, Rahal M, Al Nabulsi M, et al. Chronic kidney disease awareness among the general population: tool validation and knowledge assessment in a developing country. BMC Nephrol [Internet]. 2022;23(1):1–11. Available from: https://doi.org/10.1186/s12882-022-02889-2

13. Vinhas J, Aires I, Batista C, Branco P, Brandão J, Nogueira R, et al. RENA Study: Cross-Sectional Study to Evaluate CKD Prevalence in Portugal. Nephron. 2020;144(10):479–87.

14. Plantinga LC, Boulware LE, Coresh J, Stevens LA, Miller ER, Saran R, et al. Patient awareness of chronic kidney disease: Trends and predictors. Arch Intern Med. 2008;168(20):2268–75.

15. Gheewala PA, Peterson GM, Zaidi STR, Jose MD, Castelino RL. Public knowledge of chronic kidney disease evaluated using a validated questionnaire: A cross-sectional study. BMC Public Health. 2018;18(1):1–12.

16. Zibran MA, Mohammadnezhad M. Determinants of knowledge, attitude and practice in patients with both type 2 diabetes and chronic kidney disease in Fiji. F1000Research. 2019;8(May):239.

17. Yabeyu AB, Haile KT, Belay YB, Tegegn HG. Limited Public Knowledge of Chronic Kidney Disease in a Resource-Limited Setting: A Cross-Sectional Study. Int J Gen Med. 2022;15(May):4997–5003.

18. Okoro RN, Ummate I, Ohieku JD, Yakubu SI, Adibe MO, Okonta MJ. Kidney Disease Knowledge and Its Determinants Among Patients With Chronic Kidney Disease. J Patient Exp. 2020;7(6):1303–9.

19. Sahu G, Kumar S, Acharya S, Talwar D, Annadatha A, Patel M, et al. The Act of Prevention: Knowledge, Attitudes, and Perception Among Caretakers of Kidney Disease Patients in Rural Wardha District of Central India. Cureus. 2022;14(3):2–11.

20. Kovesdy CP. Epidemiology of chronic kidney disease: an update 2022. Kidney Int Suppl [Internet]. 2022;12(1):7–11. Available from: https://doi.org/10.1016/j.kisu.2021.11.003

21. Jager KJ, Kramer A, Chesnaye NC, Couchoud C, Sánchez-Álvarez JE, Garneata L, et al. Results from the ERA-EDTA Registry indicate a high mortality due to COVID-19 in dialysis patients and kidney transplant recipients across Europe. Kidney Int [Internet]. 2020 Dec;98(6):1540–8. Available from: https://linkinghub.elsevier.com/retrieve/pii/S0085253820310814

22. Hirsch JS, Ng JH, Ross DW, Sharma P, Shah HH, Barnett RL, et al. Acute kidney injury in patients hospitalized with COVID-19. Kidney Int. 2020;98(January):209–18.

23. European Kidney Health Alliance (EKHA). Call to Action: Improving prevention, treatment and care of Chronic Kidney Disease in the aftermath of COVID-19. . 2021;

24. Gabinete do registo da Doença Renal Crónica, Sociedade Portuguesa de Nefrologia. Portuguese Registry of Dialysis and Transplantation 2021 [Internet]. 2022. Available from: http://www.spnefro.pt/tratamento_da_doenca_renal_terminal/2018/tratamento_da_irct/305

25. Vanholder R, Annemans L, Brown E, Gansevoort R, Gout-Zwart JJ, Lameire N, et al. Reducing the costs of chronic kidney disease while delivering quality health care: A call to action. Nat Rev Nephrol. 2017;13(7):393–409.

26. Sociedade Portuguesa de Nefrologia. Plano Nacional de Saúde 2021-2030: Sociedade Portuguesa de Nefrologia preocupada com a não priorização da doença renal crónica. Raio X [Internet]. 2022 [cited 2022 Nov 10]; Available from: https://raiox.pt/plano-nacional-de-saude-2021-2030-sociedade-portuguesa-de-nefrologia-preocupada-com-a-nao-priorizacao-da-doenca-renal-cronica/

27. Elisabeth Stømer U, Klopstad Wahl A, Gunnar Gøransson L, Hjorthaug Urstad K. Health Literacy in Kidney Disease: Associations with Quality of Life and Adherence. J Ren Care [Internet]. 2020;46(2):85–94. Available from: http://dx.doi.org/10.1111/jorc.12314

28. Taylor DM, Fraser SDS, Bradley JA, Bradley C, Draper H, Metcalfe W, et al. A systematic review of the prevalence and associations of limited health literacy in CKD. Clin J Am Soc Nephrol. 2017;12(7):1070–84.

29. Kita Y, Machida S, Shibagaki Y, Sakurada T. Fact-finding survey on health literacy among Japanese predialysis chronic kidney disease patients: a multi-

institutional cross-sectional study. Clin Exp Nephrol [Internet]. 2021;25(3):224–30. Available from: https://doi.org/10.1007/s10157-020-01982-w

30. Boonstra MD, Reijneveld SA, Westerhuis R, Tullius JM, Vervoort JPM, Navis G, et al. A longitudinal qualitative study to explore and optimize self-management in mild to end stage chronic kidney disease patients with limited health literacy: Perspectives of patients and health care professionals. Patient Educ Couns [Internet]. 2022;105(1):88–104. Available from: https://doi.org/10.1016/j.pec.2021.05.016

31. Taylor DM, Bradley JA, Bradley C, Draper H, Dudley C, Fogarty D, et al. Limited health literacy is associated with reduced access to kidney transplantation. Kidney Int [Internet]. 2019;95(5):1244–52. Available from: https://doi.org/10.1016/j.kint.2018.12.021

32. Boonstra MD, Reijneveld SA, Navis G, Westerhuis R, de Winter AF. Co-creation of a multi-component health literacy intervention targeting both patients with mild to severe chronic kidney disease and health care professionals. Int J Environ Res Public Health. 2021;18(24).

33. Cavanaugh KL, Osborn CY, Tentori F, Rothman RL, Ikizler TA, Wallston KA. Performance of a brief survey to assess health literacy in patients receiving hemodialysis. Clin Kidney J. 2015;8(4):462–8.

34. Burke MT, Kapojos J, Sammartino C, Gray NA. Kidney disease health literacy among new patients referred to a nephrology outpatient clinic. Intern Med J. 2014;44(11):1080–6.

35. Nakagawa N, Nishio S. Knowledge of Chronic Kidney Disease among the General Population: A Questionnaire Survey in Hokkaido Prefecture, Japan. J Pers Med. 2022;12(11).

36. Assiry A, Alshahrani S, Banji D, Banji OJF, Syed NK, Alqahtani SS. Public Awareness of Chronic Kidney Disease in Jazan Province, Saudi Arabia—A Cross-Sectional Survey. Healthc. 2022;10(8):1–14.

37. Luo L, Zhang M, Chen HF, Tang F, Fu LZ, Zhang DJ, et al. Validity, reliability, and application of the electronic version of a chronic kidney disease patient awareness questionnaire: a pilot study. Postgrad Med [Internet]. 2021;133(1):48–56. Available from: https://doi.org/10.1080/00325481.2020.1801029

38. Chow KM, Szeto CC, Kwan BCH, Leung CB, Li PKT. Public lacks knowledge on

chronic kidney disease: Telephone survey. Hong Kong Med J. 2014;20(2):139–44.

39. United Nations. Transforming our world: The 2030 Agenda for sustainable development. 2016.

40. Dyakova M, Bellis M. Public Health Wales International Health Strategy: Nationally Focused, Globally Responsible. Vol. 27, European Journal of Public Health. 2017.

41. Willis K, Cheung M, Slifer S. KDIGO 2012 Clinical Practice Guideline for the evaluation and Management of Chronic Kidney Disease. Off J Int Soc Nefrol. 2013;3(1).

42. AKF Medical Advisory Committee. American Kidney FUnd [Internet]. Stage 5 chronic kidney disease. 2022 [cited 2022 Dec 8]. Available from: https://www.kidneyfund.org/about-us/medical-advisory-committee?s_src=website&s_subsrc=Chronic kidney disease %28CKD%29 %7C AKF%27s Medical Advisory Committee

43. Coelho A, Diniz A, Hartz Z, Dussault G. Gestão integrada da doença renal crónica: análise de uma política inovadora em Portugal. Rev Port Saude Publica. 2014;32(1):69–79.

44. Divisão de Literacia, Saúde e Bem-Estar D de S de P da D e P da S. Plano de ação para a literacia em saúde. Direção Geral da Saúde [Internet]. 2019;6. Available from: https://www.dgs.pt/em-destaque/programa-nacional-de-educacao-para-a-saude-literacia-e-autocuidados.aspx

45. Cohen J. Statistical power analysis for the behavioral sciences. 2nd editio. New York: Lawrence Erkbaum Associates; 1988.

46. Filgueiras de Assis MV, Angelo M. The impact of chronic kidney disease: experiences of patients and relatives from the extreme north of Brazil. Investig y Educ en Enfermería [Internet]. 2018 Feb 15;36(1):e02. Available from: https://revistas.udea.edu.co/index.php/iee/article/view/331942

47. Tavakoly Sany SB, Behzhad F, Ferns G, Peyman N. Communication skills training for physicians improves health literacy and medical outcomes among patients with hypertension: A randomized controlled trial. BMC Health Serv Res. 2020;20(1):1–10.

48. Shlipak MG, Tummalapalli SL, Boulware LE, Grams ME, Ix JH, Jha V, et al. The case for early identification and intervention of chronic kidney disease:

conclusions from a Kidney Disease: Improving Global Outcomes (KDIGO) Controversies Conference. Kidney Int [Internet]. 2021 Jan;99(1):34–47. Available from: https://linkinghub.elsevier.com/retrieve/pii/S0085253820312102

Additional file 1

Laypersons percentage of correct response to individual items on the questionnaire

Item No	*Question*	**Correct response**	
		Laypersons (n=1209)	
		n	%
	General aspects	**1,91 ± 0,62**	**63,66 ± 20,55**
1*	A person can lead a normal life with one healthy kidney.	1108	91,7%
2	Herbal supplements can be effective in treating chronic kidney disease.	205	17,0%
3*	Certain medications can help to slow-down the worsening of chronic kidney disease.	996	82,4%
	Kidney function	**2,94 ± 1,17**	**48,95 ± 19,49**
4*	The kidneys make urine.	749	62,0%
5*	The kidneys clean blood.	1082	89,5%
6	The kidneys help to keep blood sugar level normal.	367	30,4%
7*	The kidneys help to maintain blood pressure.	762	63,0%
8	The kidneys help to breakdown protein in the body.	214	17,7%
9*	The kidneys help to keep the bones healthy.	377	31,2%
	Kidney analysis	**2,85 ± 0,89**	**71,34 ± 22,37**
10*	A blood test.	970	80,2%
11*	A urine test.	1154	95,5%
12	A faecal (poo) test.	772	63,9%
13*	Blood pressure monitoring.	554	45,8%
	Risk factors	3,45 ± 1,41	57,44 ± 23,47
14*	Diabetes.	872	72,1%
15	Being female.	809	66,9%
16*	High blood pressure.	739	61,1%
17*	Heart problems such as heart failure or heart attack.	540	44,7%
18	Excess stress.	290	24,0%
19*	Obesity.	917	75,9%
	Signs and symptoms	**2,86 ± 1,21**	**57,27 ± 24,17**
20*	Water retention. (Excess water in the body)	1034	85,5%
21	Fever.	242	20,0%
22*	Nausea/vomiting.	616	51,0%
23*	Loss of appetite.	576	47,6%
24*	Increased fatigue (tiredness).	994	82,2%
	Score 24	**14,30 ± 3,36**	**59,60 ± 13,99**

True items.