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Seven years after "Norma 17": what has changed?

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The future's in the air
I can feel it everywhere
Blowing with the wind of change
Klaus Meine (Scorpions), 1990

ABSTRACT

Although huge medical advances have been made in dialysis treatments, older patients with higher comorbidities or poorer functional status may have limited survival advantage. In these cases, comprehensive conservative care should be considered. In Portugal in 2011 *Direção Geral de Saúde* proposed the inclusion of this modality as an option for some chronic kidney disease patients. Seven years later, as far as we know, only two nephrology departments have structured programs to follow these patients. A long road must be traveled. In this article we discuss barriers to implement comprehensive conservative programs for chronic kidney disease patients in Portugal and we suggest some ways to work around those barriers.

Key-words: barriers, chronic kidney disease, comprehensive conservative care

INTRODUCTION

Until the fourth century before Christ, it was not considered ethical to treat patients in the process of dying due of the risk of being punished for defying the laws of nature. With the spread of Christianity came the need to help sick people. Up to the 20th century, the clinical goal of care was to perform symptomatic relief, since diseases evolved according to their natural history. In the last century, medicine developed to look for the causes and to cure diseases, relegating symptomatic control to the background. It is only in the 21st century that attention is paid once more to palliative care as a need, centered not only on oncological patients but also on progressive chronic diseases where suffering may be also huge.

Chronic kidney disease (CKD) represents a good example of a serious disease that underwent an outstanding development by partially replacing organ function with technological advances in medicine. Although thousands of people owe their lives to dialysis, older patients with higher comorbidities or poorer functional status may not have the same benefits[1]. In the last two decades, growing evidence has shown that managing these patients without dialysis (called *comprehensive conservative care – CCC*) may be as good or even better care than performing dialysis[2]. The advantage of applying palliative care principles to these patients is now broadly accepted. In Portugal, Conservative Care was recognized in 2011 as an option to manage CKD patients. A clinical guideline known as "Norma 17" was released to great controversy, highlighting the option not to

proceed to dialysis in cases where benefit would be doubtful[3].

Included as an option was "*quer como primeira opção quer na suspensão de terapêutica de substituição da função renal, sempre que a situação clínica, mormente pela coexistência de comorbilidade que configure doença avançada e progressiva, faça prever que o tratamento dialítico não contribuirá para a reversão do seu estado mórbido, para o alívio da sua sintomatologia, para o prolongamento da vida do doente ou para a melhoria da sua qualidade*" (either as first choice or when renal replacement therapy is discontinued, whenever a clinical situation, mainly due to coexistence of comorbidity that is progressive, predicting that dialysis treatment will not contribute to reversal of its morbid state, to relief of its symptomatology, to prolong patient's life or to improve its quality). The guideline presupposed the assurance of clinical follow-up, namely access to adequate continued care or renal palliative care. Seven years later, as far as we know, only two nephrology departments have structured programs to follow these patients (Unidade Local de Saúde de Matosinhos, since 2013 and Centro Hospitalar de Setúbal, since 2015), although comprehensive conservative care may be provided in other facilities that have not publicized it. It is important to stress that even the number of patients who are followed in comprehensive conservative care is not known because the platform *Gestão Integrada da Doença (GID)* does not easily allow the inclusion of patients in "*Tratamento Conservador*" even if the option is available. We may perceive some barriers to the implementation of such programs. We will discuss some of the most important in Portugal, in our point of view.

BARRIERS TO IMPLEMENTATION OF COMPREHENSIVE CONSERVATIVE CARE IN NEPHROLOGY IN PORTUGAL

When a new idea or concept is born, lots of obstacles may arise. Humans tend to fear what they don't know and one of the most common defense mechanisms is to ignore the problem. We can identify barriers to implement CCC in Portugal on three levels:

– Doctors' level;
– Patients'/family level;
– Institutional level.

Doctors' perspective

Since the last century, medical schools have trained doctors to heal, have taught us to cure diseases, but not to take care of the patient as a whole (physical, psychological, social and spiritual). Death, although the most certain thing in life, is considered as a defeat. Most doctors fear facing death (or think it as their own). Additionally, deciding what to do with a patient that doesn't fit into the usual scenario usually causes anxiety. It becomes easier to follow the system that we are all familiar with: dialysis! If it is true that dialysis quality of treatment has become much better (allowing improved symptom control and quality of life), it is also true that the increase in an aging and frailer population has brought us new challenges, transforming nephrology into an almost geriatric specialty, which we were not prepared to deal with. Geriatric assessment is not part of our medical training so we do not know how to evaluate the majority of our patients. Knowledge of palliative care is also sparse. There are lots of biases on the true meaning of palliative care, which is now being recognised as very useful in the management of many chronic and non-oncological diseases. The lack of training in this area was detected as one of the most important obstacles in the implementation of a CCC program[4]. Palliative care is a discipline where we learn to handle symptoms, recognize prognosis and useful treatment options or train in communication skills to give bad news or approach a shared decision concerning advanced care planning. The absence of these abilities has led many colleagues to see withdrawal from or withholding of dialysis as denying treatment, or even as euthanasia. It becomes an option that is never considered when modalities of CKD care are presented. Prognostication is also a challenging matter. Doctors who are familiar with disease trajectories and prognostic scales are less afraid of failing or of robbing patients of hope, even if multiple studies show that patients prefer to receive a diagnosis and prognosis[5].

Patients' / Family perspective

From patients' perspective, lack or misleading information is also the most prominent barrier to CCC. It includes lack of a realistic prognostic or knowledge of all options to care for CKD (from transplant to all modalities of dialysis and also CCC). One other serious problem in the same spectrum is the difficulty of understanding information either because of health illiteracy, cognitive impairment or a geriatric condition such as hearing loss.

Table 1

Barriers to implementation of CCC in Portugal

Doctors perspective	Patient/Family perspective	Institutional perspective
Lack of preparation in	Lack of information	Lack of data:
– geriatrics	Inability to perceive info	– costs
– palliative care	Fear of abandon	– symptons
– prognostication	Fear of social punishment	– functional status
– communication skills	Lack of resources	– ACP
Fear of death	Caregiver exhaustion	*Preço compreensivo*
Death seen as a defeat		Resource scarcity

ACP – advance care planning, CCC - comprehensive conservative care

Table 2

Measures to facilitate the implementation of CCC in Portugal

Doctors' perspective	Patient/Families perspective	Institutional perspective
Compulsive education on palliative care and geriatrician	Information	Research
– during Medical School	Combat health illiteracy	Updating and expanding data
– during residency	Provide adequate resources	Standardize concepts
Learn to identify patients who may benefit from CCC		Costs evaluation
Train communication skills		Incorporation of CCC in *Preço compreensivo*
		Expansion of palliative care networks
		Multidisciplinary teams
		Evaluate de quality of care

CCC – comprehensive conservative care

From families' perspective, CCC may be felt like abandoning the relative. Some people may also fear suffering “social punishment”, feeling insecure at not providing a safe home or being able to address patient's needs. Caregiver's exhaustion may make it difficult to care for a loved one, as well. It may be responsible for many of admissions at the end of life. That is why lack of resources like a technical team support (nurse, doctor,...) or home visiting may also be seen as an important obstacle to opting for CCC.

■ Institutional perspective

At this level, lots of barriers may also be identified. They are also linked to lack of information or data. The first one (perhaps the most important in Portugal, a country that faces significant financial constraints) is costs. Worldwide, few studies address this issue, with limited data on costs, benefits or cost-effectiveness. Thus incremental health benefit has been used as a key consideration for cost evaluation[6]. In Portugal dialysis is paid on the basis of an estimated cost, negotiated with the authorities (*Preço Compreensivo*). Although “Norma 17” has determined CCC as an option, the way and amount of payment for the service has never been established.

In terms of number of treated patients, Portugal has an amazing registry[7] where it is well documented how many patients start dialysis, how old they are and their mortality, including 90 days' mortality. But in terms of withdrawing dialysis, this registry only includes numbers from the last 3 years. No single information is provided about the number of patients who had never initiated dialysis. We not even know how many patients attended a medical appointment to clarify treatment modalities, their choices and percentage of changes in these choices. We also have no information on advance care planning or which patients have a living will to restrict medical interventions, namely, dialysis. Another datum where information is null is symptoms. If dialysis treats or improves many of them, it also brings others, such as exhaustion on the day of treatment, intra-dialytic hypotension or restless leg syndrome, representing an elevated symptomatic burden, sometimes with a high intensity level. We also know nothing about functional state. In a few international studies that address the theme, institutionalized elderly patients who initiate dialysis do not improve functional status and even become worse: dementia progresses, new comorbidities are added and time spent in hospitalization or health facilities (including dialysis units) is huge[8].

Another relevant point is resource insufficiency in Palliative Care. The *Plano Estratégico para o Desenvolvimento dos Cuidados Paliativos para o biénio 2017-2018, despacho nº 14311-A/2016, de 28 de novembro* (Portuguese Strategic Plan for the Development of Palliative Care for 2017-2018) already identified the scarcity of resources in the national palliative care net[9] "*Não sendo exequível alcançar a curto prazo as estimativas calculadas dada a atual escassez de recursos, estabelecemos metas específicas e mais realistas para o biénio 2017-2018*" (Since it is not feasible to achieve in a short-term the calculated estimates given the current scarcity of resources, we have set specific and more realistic targets for the 2017-2018 two-year period). In continental Portugal there are only 18 Community Support Teams in Palliative Care (ECSCP) and many hospitals have no one dedicated to this area. Unlike many European Countries, neither palliative care nor geriatrics are clinical specialities in Portugal, which also contributes to the shortage of professionals.

A STEP FORWARD

If we wait for the perfect conditions to start a new project, we will never get into it. The first step is never easy, but it is easier when we walk an already traveled road. That means **education** is mandatory. To learn from others' experiences brings benefits and avoids unnecessary efforts or mistakes.

Probably the most important measure for implementing a CCC program is to teach concepts in geriatrician, palliative care and basic principles in comprehensive conservative care, meaning handling CKD patients without dialysis. This instruction should be obligatory and not only attended by the ones who are already interested in it. This would match CCC to peritoneal dialysis, hemodialysis or transplantation which are not learning options. That would provide expertise in stratifying patients who would benefit the most from a palliative approach, to use tools to help with prognostication, to identify and manage symptoms and to acquire communication skills to perform advance care planning and discuss end of life. This would allow the standardization of concepts and methods, as well. Although CCC was started long ago in countries such as the UK, Canada or Australia, the variety of definitions have undermined evidence in the area[10]. The standardization of tools would be useful too to allow comparison of results and increase knowledge in the area. The "surprise question" is an easy way to recognise patients in the last year of life and enable a change in attitude and to prioritize goals. Other tools for prognosis, such as the Rein Score, for symptom assessment like the POS-renal scale or a simple geriatric assessment with cognitive evaluation, daily activities capacity (functional) and frailty scale (CHAS-7) should be considered and spread in clinical practice. Once more, the value of these tools focuses on the possibility of comparing results. Scales have gaps and they should be used as an orientation, not to decide on particular cases.

That would lead us to a second critical issue: the need to create a national registry, in parallel to those which exist in other renal replacement therapies. The use of the platform *Gestão Integrada da Doença (GID)* has improved over time, from when CCC was not available as an option, until now, where we can select "*tratamento conservador*" but that means exclude the patient from registries, benefits and payments.

Money is the third critical problem. Implementation of a comprehensive conservative care program may seem to be expensive. In the USA palliative care resources have almost doubled in the last years, partially because it was demonstrated that it saved money (less hospitalization, not using unwanted resources)[6]. The reimbursement question should be discussed as well. Some advocate that it should not be paid as "*Preço Compreensivo*" but that will depend mostly on the structured model of care: a model centered on hemodialysis units that provide palliative care, a model centered on primary care medicine supported by nephrology advice, a model where nephrology departments take responsibilities or a model where palliative departments are the ones who lead. We will not discuss the different models because this would exceed the scope of this article, but we believe that nephrologists should keep their patients, who sometimes have been followed via appointments at our medical services for years. To nominate a nephrologist in each department to be responsible for a CCC program would be an important measure to implement this modality. Still on the topic of payment, reimbursement precludes performance (getting targets and quality measures). There is no consensus on the optimal economic models of implementation and even less on program evaluation. The measurement of success in a disease-focused treatment is well established, by having targets (dialysis dose, control of anaemia, phosphorus, etc.) but it is more ambiguous in a patient-centred approach.

Some of the answers to these questions may be given by research. That would be the forth turning point in

CCC implementation. Randomized clinical trials won't exist in this area because it would not be ethical, but we must create our knowledge from our experiences that should be shared. We congratulate the Portuguese Journal of Nephrology and Hypertension for increasing publications in Palliative Nephrology[11-13], but we cannot ignore that in the last years, no oral communication on this topic has been made in our national congress, *Encontro Renal.*

Last but not least a word about resources: no quality CCC program can grow individually. This highlights the importance of multidisciplinary teams to respond to a complex problem. An adequate team should be built according to local resources and circumstances, but official connections between nephrologists, palliative care doctors and general practitioners are mandatory. With them, we also should include nurses, nutritionists, psychologists and social workers both in hospital and in the community. This proximity will help to develop skills, particularly in communication, and allow the flow of information to a patient-centred care. It will also lead to the creation of common protocols and guidelines that will bring some security while we take these first steps.

CONCLUSIONS

No matter how long the walk, the most important thing to do is take the first step. And the first step to getting somewhere is not being willing to stay where we are. In this walk, we propose to learn from others' pathways to understand and optimize comprehensive conservative care in Portugal. We consider it important to standardize methods with a national CCC register; to use the same tools for screening and following-up patients; to have dedicated professionals in Nephrology departments, to promote education for trainees; to involve a multidisciplinary team in patients' and families' care; to initiate discussions on goals of care and advance care planning and to explore local resources and establish protocols of collaboration.

We hope that Comprehensive Conservative Care in Nephrology in Portugal might soon be a reality. Maybe in the next seven years acquiring abilities in palliative care will become part of nephrologists' curriculums, discussions about end of life and quality of death will occur in clinical meetings, a dignified withdrawal of dialysis may take place with adequate support and a patient centered care will became a priority. Using Martin Luther King's famous speech because equally so we "*have a dream that one day*" the nephrology community "*will rise up and live out the true meaning of*" caring for different CKD patients with different options, which are not less good than others, just different. In the same way that peritoneal dialysis or transplantation do not fit all. We also "*have a dream today!*" of a better care in the future.

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