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LETTER TO THE EDITOR

Qualitative approach to better understand the trajectory of patients with early and moderate stage CKD

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The management of patients with chronic kidney disease (CKD) is complex. Although well-defined in the advanced stages, obstacles in terms of organization of care and therapeutic management persist [1]. The organization of the screening phase and the articulation between primary and secondary care actors is a matter of debate and needs to be better studied (why, when and how), especially as this is an issue for optimizing patient followup in all countries [2]. Guidelines for management, and in particular referral to nephrologists, are different and partially address the management of heterogeneous prognoses among at-risk populations [3]. Although the involvement of primary care providers in early-stage management seems essential to early diagnosis to preserve the nephron reserve, co-management with nephrologists remains complex in practice [4]. Recent studies show that in the field, referral of patients to nephrologists does not correspond to the recommendations [5] and the lack of secondary care providers will not allow the recommendations to be applied [6]. These difficulties encountered by primary care providers raise a number of questions that need to be explored and understood: What are their representations of early-stage renal disease? How do they make an aetiological and prognostic diagnosis? On what criteria do they refer patients to the nephrologists?

Despite recommendations for the publication of qualitative research studies, there are still solid obstacles in the medical community linked to negative representations and a lack of knowledge of these concepts and methods [7]. An Australian study addressed the inadequacy of the evidence-based medicine (EBM) model as it is used by omitting the patient's perspective and professional expertise, whereas they were included in developing the EBM concept [8]. The research and clinical community, seeking to understand the gap between guidelines and real-world practice, would benefit from publishing more original qualitative studies to disseminate missing knowledge from the experience of all stakeholders. This would help primary care professionals to clarify their interventions at an early stage and optimize referral to the nephrologist.

Qualitative research studies human phenomena in their real contexts, interpreting them through specific scientific procedures of data collection (mainly semidirected, individual or group interviews) and analysis. Phenomenological approaches allow us to understand a phenomenon based on the experience of the actors and are sources of innovative data [9]. An example of a qualitative study has been applied to polycystic kidney disease, with an emphasis on the patient's perspective through the Standardised Outcomes in Nephrology project [10]. Various international qualitative studies have explored the perspectives of some of the stakeholders in the CKD care pathway specifically in primary care [11]. The difficulties encountered by general practitioners and registered practicval nurses in announcing CKD are related to an uncertain progression to an advanced stage and the fear of worrying patients [12]. No study on early-stage CKD has integrated the experience of the different actors in the care pathway at all levels of care (patients

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and primary, secondary and tertiary care professionals), nor has it used the phenomenological semi-pragmatic approach in the analysis of the data. This method makes it possible to develop a collection device that facilitates the explanation of the lived experience and the reflexivity of the participant and to analyse them with a scientific procedure, limiting the researcher's interpretation bias. In this context, we need to plan some studies to explore and describe the management of patients with early to moderate stage CKD with the phenomenological qualitative experience of the actors (patients and health professionals), regardless of the level of recourse to care (primary, secondary and tertiary) in a large population and area.

CONFLICT OF INTEREST STATEMENT

None declared.

REFERENCES

- Raffray M, Bayat S, Campéon et al. The pre-dialysis care trajectory of chronic kidney disease patients and the start of dialysis in emergency: a mixed method study protocol. Int J Environ Res Public Health 2019; 16: 5010
- Tonelli M, Dickinson JA. Early detection of CKD: implications for low-income, middle-income, and high-income countries. J Am Soc Nephrol 2020; 31: 1931–1940
- Weckmann GFC, Stracke S, Haase A et al. Diagnosis and management of non-dialysis chronic kidney disease in ambulatory care: a systematic review of clinical practice guidelines. BMC Nephrol 2018; 19: 258
- 4. Greer RC, Liu Y, Cavanaugh K et al. Primary care physicians' perceived barriers to nephrology referral and co-

management of patients with CKD: a qualitative study. *J Gen Intern Med* 2019; **34**: 1228–1235

- Schulz C., Messikh Z., Reboul P et al. Characteristics of outpatients referred for a first consultation with a nephrologist: impact of different guidelines. J Nephrol 2022; doi: 10.1007/s40620-021-01204-w
- Torreggiani M, Chatrenet A, Fois A et al. Unmet needs for CKD care: from the general population to the CKD clinics how many patients are we missing? Clin Kidney J 2021; 14: 2246–2254
- 7. Taquette SR, Minayo MCdeS, Rodrigues AdeO. The perceptions of medical researchers on qualitative methodologies. *Cad Saude Publica* 2015; **31**: 722–732
- Fernandez A, Sturmberg J, Lukersmith S et al. Evidencebased medicine: is it a bridge too far? Health Res Policy Syst 2015; 13: 66
- Emiliussen J, Engelsen S, Christiansen R et al. We are all in it!: Phenomenological qualitative research and embeddedness. Int J Qual Methods 2021; 20: 1609406921995304
- Cho Y, Sautenet B, Rangan G et al. Standardised Outcomes in Nephrology—Polycystic Kidney Disease (SONG-PKD): study protocol for establishing a core outcome set in polycystic kidney disease. Trials 2017; 18: 560
- Nihat A, Lusignan S de, Thomas N et al. What drives quality improvement in chronic kidney disease (CKD) in primary care: process evaluation of the Quality Improvement in Chronic Kidney Disease (QICKD) trial. BMJ Open 2016; 6: e008480
- Blakeman T, Protheroe J, Chew-Graham C et al. Understanding the management of early-stage chronic kidney disease in primary care: a qualitative study. Br J Gen Pract 2012; 62: e233–e242