Personalized Approach and Precision Medicine in Supportive and End-of-Life Care for Patients With Advanced and End-Stage Kidney Disease

Sara N. Davison, MD, MSc

Summary: Kidney supportive care requires a highly personalized approach to care. Precision medicine holds promise for a deeper understanding of the pathophysiology of symptoms and related syndromes and more precise individualization of prognosis and treatment estimates, therefore providing valuable opportunities for greater personalization of supportive care. However, the major drivers of quality of life are psychosocial, economic, lifestyle, and preference-based, and consideration of these factors and skilled communication are integral to the provision of excellent and personalized kidney supportive care. This article discusses the concepts of personalized and precision medicine in the context of kidney supportive care and highlights some opportunities and limitations within these fields.

Keywords: Precision medicine, personalized medicine, kidney supportive care, symptom management, end-stage kidney disease, prognosis

Despite advances in predialysis care and dialysis technology over the past several decades, people with advanced chronic kidney disease (CKD) continue to have high mortality and poor outcomes including physical, emotional, and spiritual suffering and low quality of life (QOL).[1]

This lack of progress is largely attributable to inadequately addressing the needs of patients.

To help address this, kidney supportive care increasingly is being recognized as a clinical and research priority.[1] Kidney supportive care is care aimed at improving the QOL for CKD patients throughout the continuum of their illness. This includes meticulous symptom management; patient-specific estimates of prognosis; advance care planning; the consideration of treatment options such as conservative kidney management (CKM), that is, nondialysis care and the appropriate and timely withdrawal of dialysis; as well as emotional, social, and spiritual support (Fig. 1). This care can be provided together with therapies intended to prolong life, such as dialysis. It also includes end-of-life care. The underpinning of kidney supportive care is a highly personalized or patient-centered approach to care that integrates culturally sensitive shared decision making to understand and prioritize the components of medical care most important to the patient and to ensure those priorities guide clinical decisions. Given the tremendous variability in patient trajectories and outcomes and the highly personalized approach required to provide quality kidney supportive care, precision medicine has been proposed as a potential solution to this problem. This article aims to discuss the concepts of personalized medicine and precision medicine in the context of kidney supportive care and to highlight potential opportunities and limitation within these emerging fields.

DEFINING PERSONALIZED AND PRECISION MEDICINE

The nomenclature around personalized medicine and precision medicine is confusing and often involves the use of other terms such as individualized or stratified medicine. These terms, however, are not necessarily synonymous, depending on how they are used. For the purposes of this article the term *precision medicine* refers to the tailoring of diagnostics or therapeutics to individual patients based on their unique genetic and physiologic characteristics.[2] Although this is certainly a personalized approach to care, I define personalized medicine as a much broader term that also considers the unique life circumstances and preferences of an individual (Fig. 2).[3] This includes psychosocial, spiritual, and cultural factors, which influence a patient's illness experience, symptom burden, and their preferences for care. Within this context, precision medicine is an extension of traditional personalized care. Potential opportunities and limitations of precision medicine within the framework of personalized care will be discussed for the key components of kidney supportive care.

THE POTENTIAL ROLE OF PRECISION MEDICINE IN SYMPTOM MANAGEMENT

Advanced and end-stage kidney disease is associated with a high symptom burden and patients experience

Division of Nephrology and Immunology, Department of Medicine, University of Alberta, Edmonton, Alberta, Canada.
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Address reprint requests to Sara N. Davison, Division of Nephrology and Immunology, Department of Medicine, University of Alberta, 11-113L Clinical Sciences Building, Edmonton, Alberta, Canada T6G 2G3. E-mail: sara.davison@ualberta.ca
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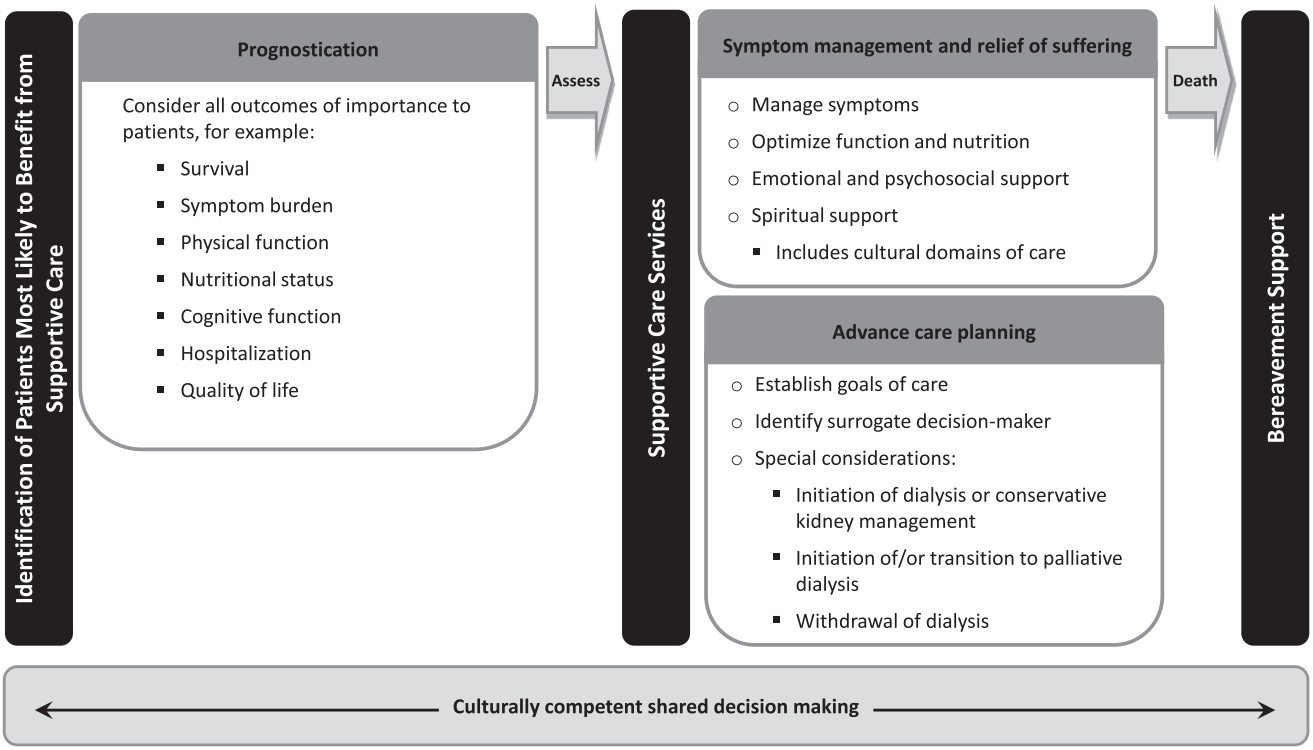

Figure 1. Key components of kidney supportive care.

complex clusters of symptoms including pruritus, restless legs syndrome (RLS), pain, fatigue, anorexia, nausea, insomnia, anxiety, and depression.[4-6] Syndromes such as malnutrition, protein energy wasting. and frailty also are common, leading to muscle and fat loss and cachexia.[7] These factors profoundly compromise patients' QOL. Although dialysis may address some symptoms such as fatigue, anorexia, nausea, and vomiting, especially for more robust individuals with limited comorbidity, it appears to do little to address symptoms in more frail patients, and often adds to their overall symptom burden. In the meantime, chronic inflammation, malnutrition, and frailty continue to progress. The pathophysiology of these symptoms and syndromes remain poorly understood. Although biochemical abnormalities may contribute to symptom burden, they do not appear to be the sole or even major drivers. We have limited, if any, means to prevent symptoms, we lack biomarkers to predict onset and progression, and we lack effective treatments that target the underlying causes.

There likely are multiple co-existing mechanisms involved, beyond abnormal biochemistry, for the symptoms and progressive functional and nutritional decline associated with advanced CKD. Anemia may exacerbate fatigue, exertional dyspnea, weakness, and weight loss. However, there is no specific hemoglobin level at which

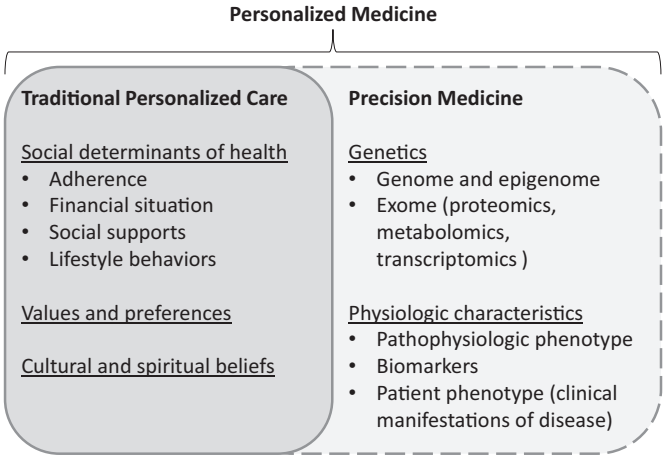

Figure 2. Defining personalized medicine.