Epilogue

Renal supportive care (RSC) as a concept and practice has gradually expanded in recent years. A growing understanding of the interface of nephrology, palliative medicine, and primary care has emerged. As such, the publication of this supplement is significant in that it is the first of its kind in India to explore that interface. It coincides with a growing recognition by the international nephrology community of the importance of RSC. In recent years, two landmark documents have highlighted the need for, and future of, collaboration across disciplines in the care of patients with end-stage kidney disease (ESKD). The first emanated from Kidney Disease: Improving Global Outcomes (KDIGO) International Meeting on RSC[1] and the second from a summit hosted by the International Society of Nephrology on increasing access to integrated care, including RSC, as part of Universal Health Coverage.[2] Both meetings had Indian representation.

In addition to coinciding with the international statements discussions, this supplement also takes advantage of a growing body of evidence in RSC across its constituent elements, including factors relevant in decision-making around commencing or withholding dialysis, where choice exists, especially for older, frail, and highly comorbid patients; symptom management across the chronic kidney disease (CKD) trajectory with or without dialysis; and principles of advance care planning and care of the dying patient with ESKD. Correctly, that evidence, especially when it comes to be applied to the cultural, religious, and social dimensions of medical decision-making in India, needs to reflect the regional context and the supplement reflects this.

Every country has its own share of challenges in providing healthcare to its community. For nephrology in India, there are significant issues in terms of accessibility to and affordability of renal replacement therapy. Many patients, as a result, commence on a conservative pathway of management, not through choice but through circumstance. That raises an internal debate within nephrology: What is its role in the care of patients with ESKD who are not on dialysis? Then again, for those who are on dialysis, what may be done to reduce their distresses? How can their autonomy to engage in decision-making be strengthened? This publication answers these questions by outlining the respective contribution of the best of nephrology and palliative medicine in the care of these patients.

RSC is not simply conservative care. It is an integrated system of care for all patients with ESKD, whether or not receiving renal replacement therapy. Practically, this means that patients on dialysis and on a conservative care pathway should have care input of all disciplines as indicated, including nephrology. It also means that, rather than referring patients to primary care or palliative care with no further input, nephrologists have an ongoing role for those on a conservative pathway.

Given the numbers of patients how can this be achieved in the context of India? Creativity and local relevance would be key. Possible models include (i) initiating RSC clinics with a trained team at different clinical settings of nephrology facility; the outpatient clinic, the dialysis center, and dialysis review clinic in a phased manner, (ii) creative reorientation of resources (utilization of volunteers trained in Integrated Palliative Care Outcome Scale-Renal), activating triggers for referral to institution-based palliative care/multidisciplinary professionals, (iii) developing capacity for RSC in-house of nephrology trainees and renal nurses, (iv) facilitating a practical process for nonnephrology personnel to access the expertise of nephrologists, when caring for CKD patients in the community, etc.

What of the future? Academic dialogue among experts, as begun with the consultation meeting of thought leaders in Manipal in 2019, under the auspices of the Indian Society of Nephrology, followed by this publication, marks a fine beginning in this process. The intentionality of the professional body, when reflected in the national policies, standards, and the educational activities: undergraduate and postgraduate curricula of healthcare professionals, continued medical education, and conference proceedings, will ensure awareness, access, and availability of RSC in India in the long run. Further research with studies done in India, on large populations with CKD can enhance the knowledge base relevant to the region. India would then be poised to develop clear guidelines that are strategic, implementable and amenable to revisions along with the growing science of renal supportive care.

Challenges are multiple: Improving access to safe, reliable renal replacement therapy where medically appropriate, developing resources and capacity for RSC with regional relevance, access to essential medicines, and an openness by all disciplines to working together to name a few.

Language skills are critical in the journey toward deep caring. Language invariably leads to perspective and practice. Employing good communication skills during clinical consultation is critical in the journey toward deep caring. The phrases used for enquiry when listening to the medical history of the patient, helps comprehend patient perspectives and align care-plans. For e.g., a simple modification in consultation language by the physician: ….I see …and then, what did you do? versus I see …and then, how did you feel? ...can surface emotional turmoils within, which may have gone unnoticed. The skills to identify priorities and empower families for appropriate decisions within the complex sociocultural environment of collective autonomy are trainable, especially during formative years. Confidence in expressing

empathy is seen in professionals trained under clinicians who express empathy consistently in their professional practice.

Equally, multiple opportunities exist to broaden perspectives and enhance capacities. Collaborative beginnings provide such opportunities, where the capacities of renal medicine and palliative care merge, with each discipline bringing its own skills, each learning from the other, and each input vital for patients to receive the best care. High-quality RSC, for all patients with ESKD, whether or not receiving renal replacement therapy, emerging from authentic and seamless integration, will assuredly enhance the comfort and dignity of CKD patients across the disease trajectory, across setting, and across their life spans.

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