Advancing Palliative Care in Patients With CKD: From Ideas to Practice

Helen H.-L. Chiu, Donna M. Murphy-Burke, Sarah A. Thomas, Yuriy Melnyk, Alexandra L. Kruthaup-Harper, Janghu (James) Dong, Ognjenka Djurdjev, Sushila Saunders, Adeera Levin, Mohamud Karim, and Gaylene M. Hargrove, on behalf of the BC Renal Palliative Care Committee

A palliative approach to care focuses on what matters most to patients with life-limiting illness, including chronic kidney disease (CKD). Despite recent publication of related clinical practice guidelines in nephrology, there is limited information about how to practically implement these recommendations. In this Perspective, we describe our experience integrating a palliative approach within routine care of patients with CKD glomerular filtration rate categories 4 and 5 (G4-G5) across a provincial kidney care network during the past 15 years. The effort was led by a multidisciplinary group, tasked with building capacity and developing tools and resources for practical integration within a provincial network structure. We used an evidence-based framework that includes recommendations for 4 pillars of palliative care to guide our work: (1) patient identification, (2) advance care planning, (3) symptom assessment and management, and (4) caring of the dying patient and bereavement. Activities within each pillar have been iteratively implemented across all kidney care programs using existing committees and organizational structures. Key quality indicators were used to guide strategic planning and improvement. We supported culture change through the use of multiple strategies simultaneously. Altogether, we established and integrated palliative care activities into routine CKD G4-G5 care across the continuum from nondialysis to dialysis populations.

Chronic kidney disease (CKD) at advanced stages is characterized by high mortality and morbidity comparable to those living with advanced cancer.1-3 In Canada, most patients with CKD glomerular filtration rate (GFR) categories 4 and 5 (G4-G5) are older than 65 years with 5-year survival while receiving dialysis being ~38.9% for those who initiated at 65 to 74 years old and 25.3% for those who initiated at older than 75 years.4 Functional and cognitive decline results in difficult end-of-life (EOL) conversations involving patients, families, and health professionals. Therefore, an integrated approach to timely advance care planning (ACP) and palliative care spanning the continuum of CKD care is needed.

It is well accepted that a palliative approach is essential for comprehensive care of patients with advanced CKD.5,6 Although published guidelines for supportive and palliative care in nephrology exist,5,7-10 there is limited information about how to systematically adopt a palliative care theoretical framework into routine care. Adopting evidence-based recommendations involves facilitating and sustaining change in culture and practice within complex and dynamic health care systems. In this Perspective, we describe our experience in integrating a palliative approach in the standard clinical care of patients with CKD G4-G5 across a provincial kidney care system in British Columbia (BC), Canada. We consider its applicability to other health systems.

What Infrastructure Has Enabled System-Wide Implementation?

BC Renal (BCR) was established in 1997 to enable a cohesive approach to delivering kidney care across 1 province within a closed health care system. It is a network within the Provincial Health Services Authority and reports to the BC Ministry of Health (Fig S1). BCR is responsible for planning, funding, coordinating, and monitoring the decentralized delivery of kidney care services through the regional renal programs. Work is accomplished through provincial committees (eg, Palliative Care Committee) consisting of health professionals, researchers, and patients who work collaboratively to plan, strategize, and guide various aspects of CKD care, including the development of clinical standards, guidelines, and tools. BCR provides administrative and technical support to these committees and facilitates collaboration across multiple committees.

As a network, we serve nearly 20,000 patients with advanced CKD; more than 3,400 patients receive dialysis and the rest are patients receiving nondialysis kidney care. All these patients may benefit from ACP and aspects of palliative care to various extents. In 2004, the network identified palliative care as a key priority and since then has launched a series of activities to foster a culture for embracing a palliative approach to CKD care.

Our program was novel at the time of inception. Thereafter, key provincial and national strategies (eg, Provincial EOL Care Action Plan11 and The Way Forward National Framework12) were developed. These strategies have raised awareness regarding ACP and palliative care in those living with life-limiting illness and thus support the ongoing culture shift within the medical community toward integrating a palliative approach to advanced CKD care. Furthermore, the effective integration of the palliative approach to CKD care is aided by partnerships with palliative care organizations in the larger medical community (including the BC Centre for Palliative Care, the University
of British Columbia Division of Palliative Care, Victoria Hospice, and others).

What Does a Palliative Approach to CKD Care Look Like in a Kidney Care System?

BCR has identified enhanced quality of life for patients with CKD G4-G5 as a key priority and thus the delivery of high-quality palliative and EOL care for patients with CKD is part of that mission. Figure 1 illustrates a timeline of key milestones and supportive events for integrating palliative care throughout the continuum of CKD care.

Framework Development

Since 2004, BCR launched a series of engagement activities, consultations, and discussions around elements of palliative care. A diverse group of stakeholders was involved in the process, including content experts in both nephrology and palliative care, patient partners, physicians, and allied health professionals of the kidney care community. From the education sessions and early planning process between 2005 and 2007, it became clear that common language pertaining to palliative and EOL care within nephrology was needed. As such, BCR formed a provincial working group with representatives of each stakeholder group to synthesize existing evidence in the literature at the time and develop a formal provincial framework for palliative and EOL care.

The EOL Framework was published in December 2009 with recommendations to support the delivery of high-quality palliative and EOL care for people with advanced CKD regardless of where they lived in the province. The document overtly describes the disease trajectory of patients and articulates 4 pillars in renal palliative care: patient identification, ACP, symptom assessment and management, and caring of the dying patient and bereavement. Critically, it covers the physical, psychosocial, and spiritual needs of the patient. Table S1 outlines the recommendations and progress to date for the key components for embracing palliative care in patients with estimated GFR < 15 mL/min/1.73 m² in dialysis and nondialysis care.

Strategic Implementation

From the beginning, our implementation approach was to build capacity across the kidney care professional workforce. The fundamental concept is that most relevant skills can be integrated into the existing roles of kidney care professionals. Instead of deploying a few individuals with specialized roles, broader education of many allows more
sustainable uptake across the provincial renal network and more effectively facilitates culture change. This approach also intends to empower leaders and other kidney care professionals to catalyze the culture change. The program was not based on any specific theory of behavior change but rather was designed primarily to address pragmatic considerations.

A series of multipronged activities that enabled the integration of a palliative approach to routine CKD care include the following.

**Champions for Change**
Recommendations as articulated in the EOL Framework were iteratively adapted provincially and regionally by distributed leadership through regional champions. These champions, who were self-identified or recruited by program leaders, include nephrologists, nurses, social workers, spiritual health specialists, data coordinators, pharmacists, managers, dietitians, and patients. Each brings unique expertise in aspects of renal palliative care (Table S2) and works within the renal programs for continual improvement in integrating quality palliative care into routine CKD care. They regularly meet with the BCR Palliative Care Committee to share best practices, develop work plans, and strategize for and monitor palliative care in the provincial network. Physician leadership and role modeling in the committee are critical to augmenting collaboration and capacity building. Engagement of committee members with other BCR committees further enables consistent messaging and integration of palliative care across the care continuum.

**Education and Training**
Initially, an intense series of training and education sessions were developed to build capacity in renal palliative care among both regional champions and frontline clinicians. Continual province-wide education on various topics of renal supportive and palliative care is delivered by provincial and international keynote speakers through provincial rounds (co-sponsored with University of BC Division of Nephrology), virtual conferences, and BC Kidney Days, an annual conference for kidney and transplant care professionals in BC. Regional workshops are funded by BCR and led by the regional champions in collaboration with the content experts for more “hands on” and experiential learning.

**Tools and Resources**
Many tools and resources for health professionals and patients were developed by the BCR Palliative Care Committee in collaboration with other modality-specific (eg, nondialysis kidney care, hemodialysis, and peritoneal dialysis) committees and external partners to support the integration of various aspects of a palliative approach to kidney care. A collection of clinical algorithms was developed, including those for symptom management, conservative care and supporting patients who are nearing the EOL.

An information system with real-time reporting functions for documentation of symptom management and ACP is another critical resource that enables our efforts. BCR has a province-wide clinical information system, Patient Records and Outcome Management Information System (PROMIS), which provides data to guide improvement efforts and use of health care resources for patients receiving kidney and transplant care. Specific modules in PROMIS were developed for symptom management and ACP documentation. These components allow systematic gathering of information for monitoring and evaluation, which is critical to optimizing outcomes.

**Patient Engagement**
Since 2012, patients with various lived experiences of CKD have been integral members of the BCR Palliative Care Committee. These patients work collaboratively with health professionals in promoting and improving palliative care. Specifically, they contribute their stories and unique perspectives and help the committee focus on what matters most to those affected by CKD. Patient voices have been shown to enable a culture shift in health professionals and facilitate improvement of health care provision and delivery.

**Financial Support for Change Management**
BCR provides financial and sustained project management support to supplement the implementation within each renal program and as a provincial network. The funding supports corresponding change management activities (eg, education, meetings, data collection, and analysis).

**Where to Focus in Advancing a Palliative Approach to CKD Care?**
We strategically focus on pillars with stronger evidence of tools and resources (ie, more certainty) that are most applicable to any kidney care settings. Furthermore, as we gain more insights about embracing a palliative approach to care in those with life-limiting illness, we recognize that aspects of it are essential to all patients with advanced CKD. Thus, we have adopted a broader approach in normalizing the conversations and practice instead of being “selective” and triaging the care approach. To further guide our evolving path to advance renal palliative care, 5 years after the publication of the EOL Framework, an interim audit was conducted to verify implementation progress (Item S1). In response to the audit findings, key quality indicators were identified using the modified Delphi technique. Table 1 summarizes the key quality metrics in guiding our efforts in the 2 targeted pillars as follows.

**ACP: Formalizing the Process**
ACP allows for patients’ wishes, values, and goals of care to be discussed among health professionals, patients, and
their family. Because ACP has become a priority in the province, resources and education are made available by the Ministry of Health and the regional health authorities. Furthermore, formal ACP training for multidisciplinary team members has been supported by the regional health authorities.

In the 2014 survey (interim audit), 83% of respondents were aware of the ACP strategies within their renal programs. Furthermore, 57% of respondents had received training in ACP and most of them indicated that they “strongly agree” or “agree” that their training equipped them with the necessary skills to have ACP conversations with patients. We aim to make ACP discussions more frequent and achieve better documentation of ACP discussions in PROMIS, in which health professionals can track ACP activities of individual patients and generate clinic- or unit-level reports of ACP activities. Aligning progress in this pillar with other efforts in promoting person-centered care (eg, patient goal setting) may better integrate the various patient-oriented conversations into routine care.

**Symptom Assessment and Management: Systematizing Practice**

In 2010, one of the renal programs piloted routine systematic symptom assessment and management using My Symptom Checklist, a modified version of the ESAS-r:

**Table 1. Key Quality Metrics for Implementation of Palliative Care Approach**

<table>
<thead>
<tr>
<th>Measure Type</th>
<th>ACP</th>
<th>Symptom Assessment &amp; Management</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Structure</strong></td>
<td>• Funding model for longitudinal care of patients</td>
<td>% assessed for symptoms within 6 mo</td>
</tr>
<tr>
<td></td>
<td>• Committee with multidisciplinary involvement including health authority representation and patient partners</td>
<td>% initiated symptom assessment within 6 mo</td>
</tr>
<tr>
<td></td>
<td>• Knowledge dissemination mechanism (eg, events and communications)</td>
<td>% of patients with key symptoms (anxiety, pruritus, pain, insomnia, and depression) by severity level (mild, moderate, severe)</td>
</tr>
<tr>
<td></td>
<td>• Health information system that captures palliative care and ACP documentation</td>
<td>Mean and median total score for distress due to symptom burden</td>
</tr>
<tr>
<td><strong>Process</strong></td>
<td>% of patients with any ACP record</td>
<td>% of patients with any ACP record</td>
</tr>
<tr>
<td></td>
<td>% assessed for symptoms within 6 mo</td>
<td>% of patients with key symptoms (anxiety, pruritus, pain, insomnia, and depression) by severity level (mild, moderate, severe)</td>
</tr>
<tr>
<td><strong>Outcome</strong></td>
<td>% of patients with legal ACP document or any other ACP document or any MOST</td>
<td>% of patients with key symptoms (anxiety, pruritus, pain, insomnia, and depression) by severity level (mild, moderate, severe)</td>
</tr>
<tr>
<td></td>
<td>% of patients with at least 1 applicable legislation checked</td>
<td>Mean and median total score for distress due to symptom burden</td>
</tr>
</tbody>
</table>

Abbreviations: ACP, advance care planning; MOST, Medical Order of Scope of Treatment.

What Are the Key Lessons Learned to Date?

During the 15 years of roll out, we observe a gradual evolution in the maturity of an integrated palliative approach to routine advanced CKD care. We have learned lessons along the way that may be applicable to other health systems (Box 1).

The provincial renal network in BC provides connections and support by which the culture and practice changes can happen consistently and collaboratively across the health system. The renal programs, which operate as discrete “business units” with local context, are able to explore ideas, learn from one another, and spread successful practices across the network. In addition, collaborations with external partners (eg, provincial or regional palliative care, home care, and primary care groups) to standardize and strategize renal palliative care provincially were timely and well integrated into the existing system.

Culture change for integrating a palliative approach to CKD care across a kidney care system takes time, in part because of discomfort felt by some health professionals and in part because of “competitive interests,” giving hope versus maintaining realistic expectations for this population. Specifically, there was inertia and resistance at the beginning to educate the renal community, socialize, and build capacity for embracing ACP and aspects of palliative care into routine practices in patients with advanced CKD. A palliative approach to care was also new to nephrology then and thus time and effort were needed to develop tools and resources to support implementation. Furthermore, the importance of timely ACP and the observed benefits of this integrated approach need to be experienced by many before adoption is more commonplace.
The identification and support of regional champions is critical because they have the potential to contextualize and effectively drive the adoption of timely integrated renal palliative care to local settings. The approach used in the provincial renal network is aligned with the essential characteristics of a palliative approach of people with chronic life-limiting illnesses, “adopts, adapts, embeds,” proposed by Sawatzky et al.20

Successful implementation is also contingent on involving the multidisciplinary teams at the frontline and patient voices throughout the process from planning to evaluation. These voices are key to bridge system planning and frontline care. Furthermore, as one of the patient partners commented, “The Committee’s accomplishments to date have set the foundation for alleviating some of the challenges faced by kidney patients. We, the Committee’s patients and health professionals, are working together to deal with the important patient issues that haven’t received sufficient focus in the past.”

A rich quantitative and qualitative data set is essential for guiding improvement.21 Having a health information system that has permitted the documentation of key parameters enables individual, local, regional, and provincial reporting to guide continuous improvement at all levels. Streamlining routinely reported metrics will help us further identify and prioritize future improvement efforts.

**What Are the Main Challenges?**

Enabling and sustaining provincial integration of a palliative approach into routine CKD care involves several key challenges: regional differences, competing priorities at the frontline, turnover of frontline staff and administrative leadership, as well as other extraneous factors. Addressing these challenges requires a continuous multipronged strategy, according to the Hierarchy of Intervention Effectiveness.22 Thus, all these strategies contribute to mobilize culture change and sustain the integration of a palliative approach to CKD care across the renal network. A thoughtful and purposeful combination of system- and people-focused evidence-based strategies has been described to be more effective.23

Despite ongoing efforts to adopt and adapt evidence-based best practices in a palliative approach to CKD care, knowledge gaps remain for effectively implementing all 4 pillars articulated in the EOL Framework. For example, limited uptake of patient identification to prioritize palliative care is partly due to lack of evidence in prognostication in the patient population. In an attempt to close the knowledge gap, our research team recently validated a well-received prediction model for 6-month mortality in patients receiving hemodialysis24 using BC data and found limited clinical utility despite reasonable performance in the BC validation cohort.25 The study findings suggest further research to enable more effective and reliable prognostication in the patient population. In the meantime, we believe that aspects of ACP and palliative care are important to any patients with advanced CKD and thus our strategies are inclusive of those with estimated GFR $< 15$ mL/min/1.73 m$^2$.

We have chosen to focus on process measures rather than outcome measures in the context of this gradual culture change due to a lack of evidence-based outcome measures in the supportive care/palliative care space. To our knowledge, there is no validated tool that can systematically assess the quality of a palliative approach in CKD care. The development of such a tool through partnership of clinical and research teams could prove useful in enabling systems, patients, and providers to evaluate the quality of life and death more accurately.

**Box 1. Key Lessons Learned in Advancing a Palliative Approach to Kidney Care**

- Network structure and organization enables culture and practice changes through shared learning and collaboration
- Culture change across a kidney care system takes time
- Contextualization of strategies to local settings and practice patterns by regional champions is critical
- Involvement of diverse frontline health professionals and patient voices throughout the process ensures relevance and effectiveness
- A rich and accessible information system with a relevant data set is essential for guiding improvement

![Figure 2. Process measures for renal palliative care: patients with symptom assessment within 6 months. Derived from data captured in Patient Records and Outcome Management Information System (PROMIS), the only province-wide clinical information system for kidney disease and transplant patients in British Columbia. Data analyses include all patients with chronic kidney disease glomerular filtration rate (GFR) categories 4 and 5 (G4-G5) registered in PROMIS (ie, total number $> 4,000$ patients semi-annually), including patients actively receiving non-dialysis kidney care with GFR $< 15$ mL/min/1.73 m$^2$, hemodialysis (HD), home HD (HHD), and peritoneal dialysis (PD) within each 6-month period.](image-url)
Conclusions

During the last 15 years, an engaged community of kidney care professionals, patients, and researchers has embarked on a series of activities to adopt an integrated palliative approach to routine care in patients with CKD G4-G5. Although our provincial renal network operates in a publicly funded health care system in which coordination across multiple health care organizations may be readily facilitated, we believe that many activities described in this report are broadly applicable to many other settings, including single health maintenance organizations or for-profit systems. Key activities include coordination of regular meetings and ongoing education of champions in the kidney care community, enabling access to supportive tools and resources, and embracing quality improvement principles. Continued engagement with key stakeholders throughout is critical. Although there is a recognized need to move ideas into practice, it is important to develop purposeful plans to ensure sustainability and true integration of palliative care practices into the care of patients living with CKD.

Supplementary Material

Supplementary File (PDF)

Figure S1: BC Renal Network diagram.

Item S1: Interim audit survey and interview questions.

Table S1: Overview of recommendations and progress in renal palliative care.

Table S2: Kidney care professionals and their content expertise in renal palliative care.

Table S3: Symptom assessment practices in health authority renal programs.

Article Information

Members of the BC Renal Palliative Care Committee: Dennis McCann, Jan Uzick, patient partners; Douglas Matsell, Lori Paille, Tanya Strubin, BC; McCann, Jan Uzick, patient partners; Douglas Matsell, Lori Paille, Tanya Strubin, BC; Claire Skjelvik, Douglas McGregor, Florence Ng, John Duncan, Kallie Kango, Karen Mahoney, Kit Yeung, Lisa Harrison, Meganne Sholdice, Oi Man Chan, Patricia Porterfield, Tara Tombari, Toni Trewerne, Vancouver Coastal Health Authority; Clair Hsieh, Donna Murphy-Burke, Helen Chiu, Janghu Dong, Jocelyn Beretta, Lee Er, Lynn Pelletier, Morgan Lam, Sanford Kong, Sidonie Buicilu, Stephanie Allan, Simone Hall, Sushila Saunders, Victoria Spooner, Yurie Melnyk, BC Renal. (List includes past and present members.)

Authors’ Full Names and Academic Degrees: Helen H.-L. Chiu, MSc, MHA, Donna M. Murphy-Burke, MHA, Sarah A. Thomas, BSN, Yurie Melnyk, MHA, Alexandra L. Kruthap-Harper, MSN, Janghu (James) Dong, PhD, Ogjenka Djurdjev, MSc, Sushila Saunders, MScN, Adeera Levin, MD, Mohamud Karim, MD, and Gaylene M. Hargrove, MD.

Authors’ Affiliations: BC Renal (HH-LC, DMM-B, SAT, YM, JD, OD, SS, AL); Fraser Health Authority, The University of British Columbia, Vancouver (ALK-H, MK); Department of Medicine, Faculty of Medicine, The University of British Columbia, Victoria (AL, MK, GMH); and Island Health Authority, British Columbia, Canada (GMH).

Address for Correspondence: Helen H.-L. Chiu, MSc, MHA, 260-1770 West 7th Avenue, Vancouver, British Columbia, V6J 4Y6, Canada. E-mail: hchiu@bcpra.ca

Support: BC Renal funded this work and had a role in defining the content of the manuscript.

Financial Disclosure: The authors declare that they have no relevant financial interests.

Acknowledgements: We thank all champions, former and current members of the BC Renal Palliative Care Committee, Pharmacy and Formulary Committee, Kidney Care Committee, and other core modality committees, being instrumental to the success of this work. We are grateful for our colleagues from the Kidney Foundation: BC & Yukon Branch, BC Centre for Palliative Care, Victoria Hospice, UBC Division of Palliative Care, and other partnering organizations for working together with us on this frontier in the past decade. Special thanks to BCR staff who have provided communications, analytical, and administrative support over the years. We appreciate Michelle Hampson and Gloria Freeborn at BCR for support in manuscript preparation.

Peer Review: Received December 20, 2019. Evaluated by 2 external peer reviewers, with direct editorial input from an Associate Editor, who served as Acting Editor-in-Chief. Accepted in revised form September 6, 2020. The involvement of an Acting Editor-in-Chief was to comply with AJKD’s procedures for potential conflicts of interest for editors, described in the Information for Authors & Journal Policies.

References


