

## Supportive Care: Economic Considerations in Advanced Kidney Disease

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### Abstract

**Kidney supportive care describes multiple interventions for patients with advanced CKD that focus on improving the quality of life and addressing what matters most to patients. This includes shared decision making and aligning treatment plans with patient goals through advance care planning and providing relief from pain and other distressing symptoms. Kidney supportive care is an essential component of quality care throughout the illness trajectory. However, in the context of limited health care resources, evidence of its cost-effectiveness is required to support decisions regarding appropriate resource allocation. We review the literature and outline the evidence gaps and particular issues associated with measuring the costs, benefits, and cost-effectiveness of kidney supportive care. We find evidence that the dominant evaluative framework of a cost per quality-adjusted life year may not be suitable for evaluations in this context and that relevant outcomes may include broader measures of patient wellbeing, having care aligned with treatment preferences, and family satisfaction with the end of life care experience. To improve the evidence base for the cost-effectiveness of kidney supportive care, large prospective cohort studies are recommended to collect data on both resource use and health outcomes and should include patients who receive conservative kidney management without dialysis. Linkage to administrative datasets, such as Medicare, Hospital Episode Statistics, and the Pharmaceutical Benefits Scheme for prescribed medicines, can provide a detailed estimate of publicly funded resource use and reduce the burden of data collection for patients and families. Longitudinal collection of quality of life and functional status should be added to existing cohort or kidney registry studies. Interventions that improve health outcomes for people with advanced CKD, such as kidney supportive care, not only have the potential to improve quality of life, but also may reduce the high costs associated with unwanted hospitalization and intensive medical treatments.**

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### Introduction

Dialysis treatment for ESRD represents one of the most expensive publically financed medical treatments in Western medicine. In the United States alone, Medicare coverage of the ESRD program costs in excess of \$31 billion per year (1), higher than many other disease-specific government-funded health care programs. Although a large investment in health care is not a problem *per se* when the investment is delivering a good return, the survival and quality of life (QOL) for some patients with ESRD, especially those with serious comorbid conditions, are poor (2,3). A recent study of health service utilization at the end of life found that older people receiving dialysis in the United States had significantly higher hospitalization rates, intensive care unit admissions, intensive procedures, and deaths in hospital compared with Medicare beneficiaries with cancer or heart failure (2,4). Interventions that improve health outcomes for people with advanced CKD, such as kidney supportive care, have the potential not only to improve QOL (5) but may also reduce the high costs associated with hospitalizations and intensive medical treatments that are not aligned with patients' preferences (6).

Kidney supportive care, which now is being used to replace the term kidney palliative care, is an essential

component of patient-centered care for those with advanced CKD (7) (see the article in this Moving Points feature by Davison [8]). It focuses on culturally sensitive shared decision making (see the article in this Moving Points feature by Brown [9]), aligning treatment plans with patient goals, advance care planning, providing relief from pain and other distressing physical and psychosocial symptoms, and addressing spiritual concerns. Kidney supportive care is delivered concurrently with interventions aimed at slowing the progression of CKD and managing the complications of CKD and comorbid conditions. Kidney supportive care is relevant to patients with CKD throughout their illness trajectory, including predialysis, while on dialysis, and during conservative kidney management without dialysis (see the article in this Moving Points feature by Murtagh *et al.* [10]).

Given the competing interests for finite health care resources, evidence of the cost-effectiveness of various kidney supportive care services is required to facilitate appropriate resource planning and develop optimal care delivery models across diverse health care settings. Policymakers need evidence that an intervention or program of care represents the most efficient use of available resources and provides value for money. Economic evaluation is a systematic way of producing this evidence.

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Recent clinical practice guidelines and government policies that aim to improve the QOL of people with advanced CKD through kidney supportive care (7,11–14) have a number of resource implications. These include remuneration for screening and management of patient-reported outcomes, such as symptoms and QOL, as well as detailed communication around prognosis, shared decision making, advance care planning, and ensuring that treatments remain aligned with patient preferences and prognosis. They may also include the public financing of specialist palliative care services, the provision of hospice beds for patients with CKD, new medicines for symptom management, and a potential redirection of resources away from dialysis interventions. The current evidence base on the resource use, costs, and health outcomes of kidney supportive care is very small. However, early indications suggest that these services may produce considerable costs savings (15,16).

There is no consensus on the optimal method(s) for economic evaluation of kidney supportive care. Traditional evaluative frameworks and outcomes may not capture the true value of comprehensive kidney supportive care. This summary aims to review the current literature on the economics of kidney supportive care, highlight the challenges and key considerations associated with economic evaluation in this context, and provide ideas about how to incorporate economic evaluation alongside kidney supportive care innovations.

### Current Literature

The efficiency of health care services is predominantly evaluated within a cost per quality-adjusted life year (QALY) framework. The QALY is a composite measure that takes into account both the quantity of life (*i.e.*, survival time) and the QOL generated by an intervention. A QALY places a value weight on time in different health states, with the QALY weight often being referred to as a utility (17). A year of perfect health is worth 1 QALY, and a year of less than perfect health is worth <1 QALY. Death is considered to be equivalent to zero. However, some health states may be considered worse than death and have a negative value (17). In the cost per QALY framework, the additional (incremental) costs and additional health outcomes of one intervention compared with the next best alternative are presented to establish their cost-effectiveness and support decision making around the deployment of health care resources.

There is little published economic evidence that compares the integration of kidney supportive care with the more traditional practice of no palliative care for patients with advanced CKD. However, two published economic evaluations that compare the costs and benefits of dialysis with nondialytic care (*i.e.*, conservative kidney management) warrant additional mention, although neither study represents comprehensive kidney supportive care using contemporary definitions as described here (7).

The first study by Lee *et al.* (18) compared current practice dialysis in the United States, defined as start of dialysis when eGFR fell to <9 ml/min per 1.73 m<sup>2</sup>, and delayed start dialysis with no dialysis from a health system perspective (19). Lee *et al.* (18) used a simulation model to compare costs, life expectancy, and quality-adjusted life

expectancy. Survival after dialysis initiation and costs of dialysis were taken from the US Renal Data System (USRDS), a national registry of patients treated with dialysis. Survival for patients who did not receive dialysis was estimated from clinical data of patients with reduced kidney function receiving care in a large United States health maintenance organization. QOL estimates were sourced from a separate study of health utilities at differing levels of kidney function, with utilities for the no dialysis health state 0.08 points higher than utilities for dialysis (20). This would concur with reported observations that QOL remains stable for people treated conservatively without dialysis until the last few months of life (5). Utilities for both dialysis and no dialysis strategies in this study were on the basis of the midpoint between two published estimates using the time tradeoff method and health utilities index questionnaire. This approach to combine utilities sourced from different methods is simplistic. Better methods for combinations of multiple estimates gained through systematic reviews of the literature and use of meta-analysis and metaregression techniques are now available (3).

Specific aspects of the care services received by patients in the no dialysis group were not characterized. However, it is unlikely that the patients in this modeled cohort from 2005 received comprehensive kidney supportive care, such as management of pain and other distressing physical, psychosocial, and spiritual symptoms, and detailed communication about end of life care and advance care planning. Mean survival for current practice dialysis was 82 months, mean quality-adjusted survival was 45 months, and mean lifetime cost was \$281,640. Mean survival for no dialysis was 48 months, mean quality-adjusted survival was 29 months, and mean lifetime costs were \$135,076. Relative to no dialysis, the current practice dialysis strategy in this simulation was associated with longer patient life expectancy by an average of 34 months and higher total lifetime costs of \$146,564. The incremental cost-effectiveness ratio (ICER) for current dialysis compared with no dialysis was \$129,090 per QALY gained and \$61,294 per life year gained. The results were sensitive to increasing costs of dialysis and increasing hospitalization rates (19).

The second cost-effectiveness analysis by Teerawattananon *et al.* (21) used economic modeling to compare peritoneal dialysis and hemodialysis to no dialysis from the perspective of the Thai health system. The conservative no dialysis treatment option was characterized by restricted fluid intake, high-dose diuretics, antihypertensive drugs, calcium, bicarbonate, iron supplementation, blood transfusions, and hospital admission if required. There was no explicit mention of supportive care interventions, such as advance care planning or symptom management. Previous Thai registry evidence indicated 50% mortality with conservative kidney management within 1–3 months (somewhat shorter than estimates from most published studies); however, the starting point (*i.e.*, eGFR) from which mortality was measured was not described. Lifetime cost of conservative kidney management was 18,000 Baht. The QOL weights (utilities) used in the model were 0.60 for conservative management and hemodialysis with complications, 0.72 for peritoneal dialysis, and 0.68 for hemodialysis without complications (taken from a meta-analysis of estimates in four studies). Teerawattananon *et al.* (21) applied the same QOL utility for patients

managed without dialysis to those receiving dialysis with added complications; however, the rationale for this was not stated and would be inconsistent with utility estimates reported in the literature (20).

It was unclear whether any of the primary studies in the meta-analysis reported utilities for conservative kidney management. Relying on the perspectives of clinicians and authors of studies to assign values to certain dimensions of living and dying is unlikely to capture the crucially important perspectives of the patients themselves (22) and likely to undervalue supportive care. Scenarios were modeled for 20- and 70-year age groups. The cost-effectiveness results by Teerawattananon *et al.* (21) produced an ICER of 672,000 Baht per QALY gained for peritoneal dialysis versus conservative kidney management and an ICER of 806,000 Baht per QALY gained for hemodialysis versus conservative kidney management. Using purchasing power parity (an exchange rate that equates the price of a basket of identical goods and services in different countries) (23), these results approximate \$52,000 per QALY gained for peritoneal dialysis and \$63,000 per QALY gained for hemodialysis compared with conservative kidney management. Teerawattananon *et al.* (21) concluded that these overall results were higher than current benchmarks for cost-effective interventions; although these estimates varied by age, the gain in survival and QALYs among younger patients might justify treatment.

Unsurprisingly, both of the above economic evaluations reported that conservative kidney management was less expensive than dialysis (and offered substantial cost offsets from reduced hospital admissions) and produced fewer QALYs. The expected survival times with conservative care in the study by Lee *et al.* (18,19) (48 months) and the study by Teerawattananon *et al.* (21) (3 months) are outside estimates from many observational studies (range = 6–36 months) (5,24–27). The work by Murtagh *et al.* (10) in this series includes a detailed discussion on survival. With a fair degree of certainty, each study concluded that contemporary dialysis practice would not be considered cost effective compared with no dialysis care at current willingness to pay thresholds. This does not, however, address issues of cost-effectiveness of supportive care, although it clearly provides an imperative to look for cost-effective strategies for improving patient outcomes.

A limited retrospective analysis of costs of patients on dialysis who used hospice compared with those who did not showed lower costs; hospitalization costs accounted for most of the difference (15). We should caution that studies that compare costs between decedents and survivors may be misleading, because the comparison is based on an uncertain outcome (death) and may falsely elevate the cost of end of life care (22).

### Evidence Gaps

There are clearly large evidence gaps in the economic evaluation of kidney supportive care whether it is applied to patients predialysis, patients on dialysis, or conservatively managed patients. Broadly speaking, the evidence gaps include robust survival estimates for patients who receive supportive care at different levels of kidney function (25,27); longitudinal QOL estimates, particularly for

older, frail people with multimorbidity, that cover the entire disease trajectory, including the last few months of life; broader measures of wellbeing beyond QOL that include capabilities (the ability to be and do the things that a person values) and treatment preferences (28–30); and costs and resource use of comprehensive and integrated specialist and community-based kidney supportive care services (22).

### Methodologic Issues

There are numerous methodologic issues arising from the economic evaluation of kidney supportive care, some of which are common to the evaluation of palliative care in general and others that are specific to people with advanced CKD.

First is the issue about the choice of appropriate comparators. Kidney supportive care for those managed conservatively has been compared with dialysis in observational studies, such as the ones described above, although not yet in a randomized trial (21,24,31). However, dialysis and conservative management are not necessarily competing alternatives, because patients who choose conservative kidney management are fundamentally different from those who choose dialysis (12,32). We note that estimates of the survival benefit of dialysis over conservative management are confounded by the characteristics of patients who choose each treatment. In this context, an evaluation that compares different models of kidney supportive care (such as early referral to specialist palliative care, joint kidney and specialist palliative care service provision, or nurse-led provision of supportive care) may be more appropriate.

Second is the issue of whether the cost per QALY framework is appropriate to evaluate kidney supportive care where the focus is on improving the patient experience and QOL through good symptom management, coordination of care, and improved communication between health care professionals and patients/families (33) rather than prolonging life. The outcomes of interest to patients and their loved ones may include health and nonhealth outcomes. For example, reassurance that end of life care will be congruent with patient wishes is unlikely to be reflected fully in QALY gains, which focus just on health. An intervention, such as hospice care, may be evaluated as less beneficial in terms of quality-adjusted survival if the benefits of hospice are not adequately captured in the utility measure (as likely seen in the studies by Lee *et al.* [18,19] and Teerawattananon *et al.*) (21) and if hospice does not produce additional survival compared with a life-extending intervention, like hemodialysis, even if hospice aligns with the patient's preferences. In addition, a traditional cost per QALY framework does not typically allow for the inclusion of costs or benefits incurred by family caregivers, particularly if these cannot be captured in health terms (34,35). Alternative frameworks that focus on capturing both health and nonhealth outcomes may be better suited to this area. These might include cost-benefit analysis (where outcomes are captured in monetary terms) (36), capability frameworks (where outcome measures are conceptually linked to an individual's ability to do and be the things that are most important to them) (37,38), or cost-consequence approaches (where there is no attempt made to value across different outcomes, but they are simply tabulated) (17).

Third, studies of palliative care for patients with cancer and other chronic diseases highlight the need for inclusion of relevant outcomes that may be different from the health outcomes traditionally used in economic evaluations. These outcomes should reflect both structure and processes of supportive/palliative care provision, such as number of hospitalizations avoided (27,39,40), hospital-free survival, and place of death (41), along with outcomes desired by patients, including the broader measures of wellbeing (such as capabilities) (28) and family satisfaction with the end of life care experience (34). Although survival and quality-adjusted survival may still be important, other outcomes, such as functional ability, symptom burden, and having care aligned with treatment preferences, are more relevant to patients as they approach the end of life (42,43).

Fourth is the challenge of data collection in a population that tends to be frail and often cognitively impaired. It can be difficult to enroll such patients in research studies, and staff may be reluctant to survey patients about their QOL or capabilities while sick or distressed. This can result in large amounts of nonignorable missing data (or informative censoring) (44). There are also issues to accommodate if obtaining data from proxy respondents (22).

Fifth, nonrandomized comparisons for kidney supportive care interventions are likely to continue for pragmatic and ethical reasons. There are specific technical challenges for comparative economic evaluations among nonrandomized cohorts. Statistical expertise is required to apply inverse probability weighting or propensity score matching techniques to account for the nonavoidable selection bias among these cohorts of patients (45).

Sixth, the time horizon for the economic evaluation of kidney supportive care can be difficult to define. Traditionally, evaluations start at the receipt of the intervention and usually finish with the death of the patient (46). Kidney supportive care is likely to occur over a longer time period than traditional palliative care for malignant conditions, which historically focused primarily on the last 6 months of life. Kidney supportive care may not have a clear start date and will be highly variable, occurring at different time points or levels of kidney function depending on the patient's symptoms and needs. The end point for interventions may be before death and reflect successful communication around treatment decisions and symptom management without further intervention required for some time. Conversely, the end point for evaluation may extend beyond the patient's death into the bereavement period of the family (22). This is particularly relevant for interventions that target improved communication or family satisfaction with care.

Seventh, evaluations of kidney supportive care, like all economic evaluations, will be country and region specific depending on the available resources (47,48). This is particularly apparent for low- and middle-income countries that have limited access to publicly funded dialysis and supportive care services (49). This affects not only the choice of comparators in the evaluation but also, the cost of service provision whether it be provided through existing renal or palliative care services, which vary greatly across countries in both acute and nonacute care settings (50).

### Future Directions

To address the issue of appropriate comparators, a useful approach might be to try to exploit the natural variation in

services offered across settings and from that, determine how different aspects of supportive care services influence outcomes (for example, assessing patient QOL and satisfaction with care *via* supportive care interventions that differ according to timing of referral, personnel involved, frequency of visits, type of assessments, and treatment algorithms for symptom management). Similarly, clinicians and researchers may choose to assess the cost-effectiveness of specific kidney supportive care interventions, such as advance care planning (51), or nephrologist-led supportive care services. Because supportive care interventions are often multifaceted, it is important that studies specify the components of care incorporated in the intervention and measure processes of care so that fidelity to the intervention can be assessed and ultimately replicated.

Large prospective cohort studies are recommended to collect data on both costs and health outcomes. Linkage to administrative datasets, such as Medicare or Hospital Episode Statistics (52), can provide detailed estimates of publicly funded resource use, such as (1) visits to specialist palliative care physicians, nurses, and community-based nurses; (2) hospitalizations related to kidney disease, symptoms, or dialysis; (3) hospice admissions; and (4) medication use for symptom management, and it can reduce the burden of data collection for patients and families. However, out of pocket costs to families for care can be substantial, and administrative data collection needs to be supplemented with patient/family surveys or resource use diaries. Longitudinal collection of QOL and functional status could be added onto existing cohort or kidney registry studies, such as the USRDS Special Study Center on Palliative and End-of-Life Care (53).

### Ways in Which Cost-Effectiveness Analysis Can Be Implemented alongside Kidney Supportive Care Service Development

The capacity to evaluate the cost-effectiveness of relevant interventions can coincide with kidney supportive care service development. The addition of resource use questionnaires, patient diaries, or linkage to administrative datasets (*e.g.*, admitted patient data and primary care data) will help identify the incremental resource use associated with supportive care provision. The incorporation of patient-centered and -reported outcomes will broaden the knowledge base around health outcomes and provide direct valuation of economic benefit. These should include health-related, utility-based QOL instruments, such as the Short Form-12 and the EuroQol-5 Dimensions. Instruments measuring capability that cover attributes important to older people (such as the ICEpop CAPability Measure for Older People) (54,55) and that address capability at the end of life (such as the ICEpop CAPability Supportive Care Measure) (30) should also be considered. Process evaluation (56), including qualitative interviews with patients predialysis, patients on dialysis, conservatively managed patients, informal caregivers, and/or bereaved families, is also important in assessing the effectiveness of supportive care services and identifying opportunities for improvement.

### Conclusion

Limited data exist on the costs, benefits, and cost-effectiveness of kidney supportive care. There is no consensus

on the optimal method(s) for economic evaluation of kidney supportive care. Traditional evaluative frameworks and outcomes should be challenged, because they may not capture the true value of comprehensive supportive care for people with advanced CKD. Financial savings are not the main consideration of cost-effectiveness analyses. Rather, an incremental health benefit that is judged to be good value for money is a key consideration. Kidney supportive care has the potential for both improved patient outcomes and reduced costs from not using unwanted, resource-intensive care pathways. Quality health economic research in this area is needed.

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#### Disclosures

None.

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