

Senior Seminar HESA 6380

Best Practices in Palliative Care for Patients with End Stage Renal Disease

With Recommendations for the Nova Scotia Renal Program

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Executive Summary

End-stage renal disease (ESRD) refers to stage 5 chronic kidney disease. Because of heavy symptom burdens and shortened life expectancies, this patient group is specifically in need of palliative care, which aims at improving the quality of life of patients suffering from a life-limiting condition and their families. Palliative care can overlap with curative treatments, but will focus more on the palliation of symptoms as the illness progresses.

Currently, each District Health Authority (DHA) has its own palliative program. There is also only one hospice in Nova Scotia, which is located in Bedford. In the Capital District Health Authority (CDHA), the palliative care program only services patients whose death is foreseen to be within the next 12 months. Patients are either admitted to the service in the hospital or stay at home (or wherever they were) with palliative care consult and support.

Advance care planning (ACP) is an important component of palliative care and refers to the process of communication among patients, families, healthcare providers and other important individuals about the patient's wishes for end of life care. The main goals of ACP are to allow the patient to have control over his/her health care and to prepare the patient and the family for the patient's death.

Common symptoms of ESRD include pain, agitation, pruritus, constipation, dyspnea, and nausea and/or vomiting. A key consideration in managing the symptoms of patients with ESRD is the pharmacokinetic properties of drugs in the presence of reduced or absent GFR. Regular and detailed pain assessment is also important, and can be best achieved through using a simple numerical scale of 1-10.

Patients with ESRD and their families often face uncertainties and complex emotion, and have difficult decisions to make. Psychosocial support refers to addressing the psychological and social needs of patients, and includes peer support networks and home visits by health providers. Supportive care for the patient and family include helping to understand and express emotions and to strengthen relationships. Spiritual care involves “being present” for people as they confront suffering and allowing them to find a way of making sense of what is happening.

Terminal care refers to caring for and supporting patients in the dying phase. It focuses on symptom relief, comfort care, preservation of dignity, and support for religious or spiritual needs. A “good death” is free of pain, brief, and peaceful, with loved ones present, and in a place where the patient has chosen to die.

Bereavement is the state of having suffered the loss of someone significant. Healthcare providers should allow the family to stay with the body and allow for silence if that is what the family wants. Displaying an obituary, attending the funeral, sending condolence cards, holding memorial services and following up with the family are all good practices.

In an acute care setting, it is important to establish an open culture that discusses death, palliative care, and supportive care during pre-dialysis meetings with patients. The core care team should be multidisciplinary and include the patient and other people that the patient wishes to be included in their care. In addition, the core care team need to meet on a regular basis to facilitate communication and have debriefs after the death of a patient.

Hospice care focuses on addressing end-of-life issues and emotions and helps patients and family manage life closures and cope with grief. Hospice palliative care can complement

and enhance active treatment or become the entire focus of care. In many jurisdictions, hospice care also extends to home palliative care, which has been shown to increase patient and family satisfaction and reduce medical costs.

Palliative care program need to education patients about their conditions and correct misconceptions they may have about palliative care. Healthcare providers also need education and training to continuously improvement their competencies in this area. Joint programs for the renal team and the palliative care team may be helpful. In addition, training needs to be workplace-based, recurrent, and led by experts and expert patients.

After examining best practices in renal palliative care across jurisdictions, this report provides four broad recommendations. The first recommendation is to expand palliative care education for healthcare providers in the renal team. Second, referral guidelines should be established and patients should be referred at diagnosis of ESRD. Third, the Nova Scotia Renal Program should develop a provincial framework for renal palliative care to minimize disparities in service delivery and improve quality of the service. Lastly, partnerships with hospices and other community palliative care supports can be explored to expand educational efforts and home palliative care services.

1. Background

Chronic kidney disease is a term that includes the five stages of renal disease, the last stage (stage 5) of which involves having a glomerular filtration rate (GFR) is less than 15 mL/min and patients are in need of dialysis or kidney transplantation (Chambers *et al.*, 2004). End-stage renal disease (ESRD) is an older expression widely used in literature to describe stage 5 patients who require dialysis to survive (Lewis *et al.*, 2006). In 2009, a total of 37,744 Canadians had ESRD, which represents a 62% increase in prevalence since 1999 (CIHI, 2010). The symptom burden of patients with ESRD is equivalent to that of patients with cancer (Saini *et al.*, 2006), thus making palliative care crucial for this patient population. In addition, “because of shorted life expectancy, end-of-life care is particularly relevant for patients with end-stage renal disease” (Moss, 2003). This report aims to highlight best practices in as well as emerging concepts about palliative care as it applies to patients with ESRD through a review of literature and frameworks on the topic. Recommendations are provided for the Nova Scotia Renal Program at the end.

2. Current Practices in Nova Scotia

All information in this section is kindly provided (through personal communication) by Heather MacDonald and Peter MacDougall, as mentioned in the “Acknowledgement” section.

Currently in Nova Scotia, each District Health Authority (DHA) has its own palliative care program as there is no provincial program for palliative care. The only hospice in the province is located in Bedford, with about 4-6 beds. This hospice is not yet fully operational and currently provides just bereavement services to the public. Unfortunately, there are likely a large number

of patients who are in need of palliative care but not referred to the program or referred only days before death, which points to the need for referral guidelines.

In CDHA, In the Capital Health District, patients are referred by their family or specialist care physician to the palliative care program, which mainly serves a consultative function. The palliative care team consists of specialist palliative care physicians and nurses, social workers, a bereavement coordinator, a spiritual care coordinator, a music therapist, and volunteers.

When the program receives a referral, it is reviewed by the triage team based on preset guidelines in order to determine the urgency of a patient's care. Patients whose death is foreseen within the next 12 months fall under the criteria of the service. When a patient with ESRD is referred to palliative care by their renal physician, depending on the prognosis of the patient, he/she may be admitted to the service, managed by the palliative care team in the clinic or at home, or deemed to not require immediate palliative care except minor symptom management consultations, in which case the physician would be advised to contact the palliative care team on an as-needed basis. A needs assessment is also conducted upon referral and the patient is either admitted as an inpatient on the palliative care ward or referred to appropriate services accordingly. For example, patients who can continue to stay at home would be referred to home consult service with supports put in place such as Victorian Order of Nurses (VON) services and Continuing Care. The palliative care role would then mainly be in managing symptoms and other aspects of end-of-life care.

Advance care planning (ACP) is done by palliative care nurses as soon as the patient is referred if it has not already been addressed. In terms of symptom management, there are

currently no clinical practice guidelines (CPGs); however, a regime is used to guide medication dosages. In addition, breakthrough pain is documented in detail on the patient's chart so that physicians can keep track of the effectiveness of the patient's medications. The Edmonton Symptom Assessment System (see Appendix E) is a requirement from Accreditation Canada, which suggests that the assessment be completed within the first 24 hours of admission. The program is currently working on a process for this. The bereavement program is 13 months. It involves group work and follow-up letters and phone calls to families throughout this time. Memorial services are also held three times a year for patients, staff and families.

One challenge for the palliative care program is the lack of resources in providing education for other clinicians who are not part of the palliative care unit but deal with patients in need of end-of-life care. As well, palliative care services are currently only available during weekdays and regular work hours due to resource restraints, although one specialist palliative physician and other services such as the VON are available after hours to provide services to patients who are at home. Another challenge is that it is difficult to get the patient's family physician to be involved in the patient's end-of-life care because these physicians usually do not work after on holidays or weekends or after 5pm. A consult nurse usually speaks with the family physician and explains the importance of their involvement.

3. Introduction to Palliative Care

The World Health Organization (WHO) defines palliative care as "an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illnesses through the prevention and relief of suffering by means of early

identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual” (WHO, 2011). The WHO also recommends that palliative care be extended beyond the patients to the caregivers and beyond death to bereavement support (Sepulveda *et al.*, 2002).

3.1 Referral to Palliative Care

Nephrologists are becoming increasingly aware that palliative care is not merely management of the illness at the end of life, but rather a supportive care pathway that leads over time to a dignified end of life for the patient (Holley, 2005). Although some authors and frameworks support the initiation of palliative care when the patient opts for conservative management (Fassett *et al.*, 2011), has decided to stop dialysis (Fassett *et al.*, 2011), or is likely to pass away within 12 months (Ministry of Health, 2001, p. 11), the majority of opinions advocate the initiation of palliative care for patients and family when ESRD is diagnosed (Nobel & Kelly, 2006; WHO, 2011; Levy *et al.*, 2004, etc.). Referral to palliative care should be guided by referral protocols, supported by advice from health professionals, and based on the person’s needs and choices (Ministry of Health, 2001, p. 11). Delayed initiation of palliative care can result in unnecessary suffering for patients and families (Davison, 2001; Moss, 2003).

When initiated at the time of diagnosis, palliative care is then not exclusive from active treatment. Interventions such as dialysis can take place alongside palliative care to maximize disease control and quality of life (Reiter & Chambers, 2004; Nobel *et al.*, 2005; Holley, 2005; Sedgewick *et al.*, 2010). As the illnesses progresses, there will be greater reliance on palliative care interventions as fewer active treatment options will be available, especially when it

becomes clear that the patient is no long benefiting from dialysis (Cohen & Germain, 2004; Lamping, 2004; Reiter & Chambers, 2004).

3.2 The Palliative Care Team

A hallmark of palliative care is the involvement of interdisciplinary teams (Mahon, 2010; Freysteinson, 2010; Cohen *et al.*, 2006). Morrison *et al.* (2008) assert that medical personnel trained to focus on one area of the human body cannot fully meet the needs of seriously ill patients by themselves. Optimal patient care requires combining technical proficiency in disease assessment and management with capacity to understand the condition and prognosis as perceived by the patient and to emotionally guidance the patient and family members (Fassett *et al.*, 2011). Collaboration between nephrologists and palliative care consultants or specialists (Cohen *et al.*, 2006), or palliative care teams consisting of a palliative care physician, advanced practice nurse, social worker, chaplain or spiritual care counselor, pharmacists and volunteers is recommended (National Quality Forum, 2006). In the Quebec palliative care network, there are also psychologists who are part of specialized interdisciplinary palliative teams in the care units of short term care centers and university medical centers (Ministry of Health and Social Services, n.d., p. 32). Family and social services assistants can visit patients and families at home under the supervision of professional and play an educational and support role to observe, listen and provide interim assistance with domestic matters (Ministry of Health and Social Services, n.d., p. 32). Whatever the composition, the palliative care team is ideally available 24/7 (National Quality Forum, 2006).

3.3 The Business Case for Palliative Care

Hospital palliative care programs can decrease critical care mortality and offset costs of care for patients who are seriously ill (Elsayem *et al.*, 2004; 2006). One study from the US that showed that a palliative care consultation program produced a net savings of \$1,696 per admission for patients who were discharged, and \$4,908 for those who died in the hospital (Morrison *et al.*, 2008a). Furthermore, patients with access to palliative care are more likely to die in a setting of their choice, and have fewer critical care admissions and shorter length of stay in the last six months of their life (Morrison *et al.*, 2008b).

3.4 Other Considerations

Patients differ on a wide range of factors which need to be taken into account when delivering palliative care services, which include the nature of their condition(s) and symptoms, living arrangements, social circumstances, pre-existing vulnerabilities such as mental health issues or learning disabilities, experience of health care to date (especially in relation to the deaths of others), approach to life and psychological wellbeing, culture factors, and spiritual and/or religious beliefs (Department of Health, 2008). In terms of the nature of their conditions, the BC Renal Agency (2009, p. 10) has developed some indicators which can identify patients with early risks of death and therefore have urgent needs for palliative care. The most powerful prognostic indicators are serum albumin, modified Charlson Comorbidity Index (CCI) (which is a questionnaire that quantifies co-morbid illness), the “surprise” question, and age.

From an administrative perspective, it’s important to ensure that patients with palliative care needs are aware of and have access to palliative care services, and that these services are

coordinated with other health services the patients is using to support the continuity of care. Having a regional or national palliative care framework for renal patients would raise awareness about the benefits of palliative care among health and disability professionals and the general population, promote better coordination and management of renal palliative care services, and minimize any disparities in service across different areas or regions (Ministry of Health, 2001, p. 12). The Irish Hospice Foundation (2008, p. 24) also supports the development of integrated care and referral guidelines to further integrate specialist palliative care teams with primary care teams and non-specialist palliative care.

4. Components of Palliative Care

The Robert Wood Johnson Foundation's Promoting Excellence in End-of-Life Care program identified pain and symptom management, psychosocial and spiritual support, advance care planning, and assistance with other decisions related to end-of-life issues as crucial components of palliative care for renal patients (RWJF, 2002; Moss *et al.*, 2004). Morrison *et al.* (2008b) stresses that the importance of psychosocial and spiritual assistance should not be underestimated because patients as well as their family face many choices and uncertainties when there is a diagnosis of failing kidneys, and patients often become aware that death may not be far off. Some other components of palliative care include patient and staff education, peer support networks, terminal care and bereavement programs (Jablonski, 2008; Brown *et al.*, 2008; Germain & Cohen, 2007; Young, 2009).

4.1 Patient Communication and Advance Care Planning (ACP)

Advance care planning (ACP) is an essential component of palliative care as identified by numerous articles in literature as well as end-of-life care frameworks from various jurisdictions.

4.1.1 Patient Communication

When patients are confronted with ESRD and all the uncertainties that are associated with it, providing patients with adequate information about their condition, prognosis, and options for treatment and support so that patients can make informed decisions regarding their care is paramount (Brown *et al.*, 2008). Many authors assert that, by providing such information and support in a timely, patient-centred and culturally-sensitive way, renal and palliative care teams can help patients make an informed decision about whether to start dialysis or when to stop it, and better plan for their end-of-life care through identifying their values and needs and involving them in end-of-life discussions in order to facilitate a dignified dying experience and death (Brown *et al.*, 2008; Cohen *et al.*, 2006; Young, 2009). Furthermore, when patients have an in-depth understanding about the likely progress of their condition(s), their fear of death can be minimized (Haras, 2008) because providing timely and appropriate information can enhance a patient's feeling of control and hope rather than diminish it (Davison & Simpson, 2006). Research also indicates that patients and families value honest discussions with healthcare providers early in the illness (Davison, 2001) and that patients who actively took part in their end-of-life discussions and decisions often had positive end-of-life experiences and achieved a "good death" (Carter *et al.*, 2004; Friedrichsen *et al.*, 2000; Royak-Schaler *et al.*, 2006, Smith, 2000).

Promoting awareness of end-of-life options and encouraging end-of-life care discussions and planning is not only the responsibility of the health care system, but also that of the entire community and the individual (PCA ACP position statement, p. 1). Death and dying needs to be seen as profound social occurrences rather than mere medical events since their meaning depends on specific social contexts within which they take place and they have broad impacts that extend beyond the individual patient (Palliative Care Australia, n.d., p. 4). Thus, “capacity to promote and support end-of life-care discussions rests within a broad social context in which the community, as well as health professionals, individual consumers, their families, significant others, and carers all have a role to play” (Palliative Care Australia, n.d., p. 4).

4.1.2 Goals of Advance Care Planning

ACP is a part of end-of-life discussions, and it refers to “a process of communication among patients, families, healthcare providers and other important individuals about the patient’s wishes for end-of-life care” (Holley, 2005). There should be an emphasis on the values and beliefs of the patient in relation to medical decisions (Fried *et al.*, 2002). The purpose of these discussions overall is to ensure the centrality of the patient’s voice in medical decision making (Palliative Care Australia, n.d., p. 3) through (Lynn & Goldstein, 2003; Singer, 1999; BC Renal Agency, 2009, p. 12, 13) a number of ways:

- Enhancing patient/family understanding of ESRD and end-of-life issues and care options;
- Identifying the patient’s key priorities in end-of-life care in order to develop a care plan;
- Identifying a substitute decision maker for medical decisions in case of incapacitation;
- Helping the substitute decision maker understand his/her role;

- Preparing a patient and the family for the patient's death;
- Promoting good healthcare decision process and a shared understanding of relevant values among the patient, the substitute decision-maker and healthcare providers;
- Allowing the patient to achieve control over his/her healthcare and
- Relieving potential burdens on loved ones and strengthen interfamily relationships.

Patients find ACP valuable in that it helps to depress their fears, prepares them for death, strengthens interpersonal relationships, and allows them to achieve control over their life (Davison, 2006). Wilkinson *et al.* (2007) also suggest that ACP in many cases provides patients comfort and security because patients know that their wishes are understood and will be respected.

ACP is best completed early and should take into consideration the progressive nature of the illness and the possibility of life-threatening complications (Lynn & Goldstein, 2003). Aside from decisions about treatment options, ACP also focuses on decisions about practical arrangements as well as on the ethical, psychosocial, and spiritual issues related to starting, withholding, and stopping treatment such as dialysis (BC Renal Agency, 2009, p. 12). Overall, ACP can be seen as an ongoing and dynamic process that addresses the holistic care of an individual and his/her family, and of which written advance directives for when the patient is no longer able to make medical care decisions in the future is only a small part (Holley, 2005; BC Renal Agency, 2009, p12; Palliative Care Australia, n.d., p. 3). There are two types of advance directives: instructional directives specify preferences, and proxy directives appoint another person as a substitute decision maker (BC Renal Agency, 2009, p. 12). Instructional directives

need to be based more on values and acceptable health states rather than specific treatments interventions (Hammes, 2001; Moss *et al.* 2004; Holley *et al.*, 2003).

4.1.3. Who is Responsible for Advance Care Planning

The literature on palliative care does not provide much information on which healthcare providers should discuss ACP with patients. In the UK, where core clinical care for renal patients is provided by the renal team with specialist palliative care advice as necessary, ACP discussions are initiated by the renal team (Brown *et al.*, 2008). The End-of-Life Framework in the province of BC (2009) also suggests that the renal team is in the position to initiate conversations pertaining to end-of-life care of the patient as research has shown that patients feel that their nephrologists are responsible for initiating and guiding ACP. In Australia, where general practice physicians have a significant role in a patient's palliative care since there is an existing patient-physician rapport, ACP is also incorporated into enhanced primary care planning in addition to acute and continuing care sectors (Department of Health and Aging, 2010, p. 11). In general, it does not seem to matter which healthcare provider assumes the responsibility of initiating advance care planning discussions as long as the provider is comfortable with and competent in end-of-life communications following adequate training (Holley, 2005; Perry *et al.*, 1996; 2003; Quill, 2000; Buckman, 1992) and the arrangement fits with a sensible and effective end-of-life care pathway.

Studies indicate that although some patients want facts about their illness and related prognosis from their physicians, but prefer to discuss preferences and future medical plans with their family (Holley *et al.*, 2003). Therefore, the primary role of healthcare providers in advance

care planning is to introduce the topic and encourage patients to discuss salient issues with their families (Lynn & Goldstein, 2003; Singer, 1999; Hines *et al.*, 1999). Providers can introduce the topic of wishes for end-of-life care whenever they are discussing prognosis or treatments with a low probability of success with patients, or during routine visits of appropriate family members (Lynn & Goldstein, 2003; Singer, 1999; Quill, 2000). The actual ACP discussion should be started when a provider would not be surprised if a patient died within the next 12 months (Lynn & Goldstein, 2003; Quill, 2000). Such conversations need to spring off positive language with an invitation for the patient to communicate and educate (Holley, 2005). For example, the provider can start with a phrase such as “I want to ensure you receive the kind of treatment you want” or ask the patient “how much do you want to know? How specific do you want me to be?” (Moss *et al.*, 2004; Quill, 2000; Buckman, 1992). Clear, honest and straight forward discussions focused on prognosis and future care options rather than technical processes, at a level understandable to the patient, helps enhance the patient’s self-reliance and eases any fears and uncertainties (BC Renal Agency, 2009, p. 13). Healthcare providers involved in the process also need to realize that ACP is likely not a onetime event but a series of discussions, and that the outcomes need to be reviewed whenever possible because patients may change their minds depending on their current state of health (Royal College of Physicians, 2009, p. 4; Seymour *et al.*, 2004; Fried *et al.*, 2007).

4.1.4 Respecting Diversity in Advance Care Planning

Dobbins (2005) found that a patient’s religious, racial and ethnic background has an impact on his/her end-of-life decisions. For example, Individuals from African-American are

more likely to seek aggressive interventions when compared to Asian populations (Nahm & Resnick, 2001). Different ethnic groups vary in their use advance directives and their values and beliefs about certain life-sustaining treatments (Valente & Haley, 2007; Searight & Gafford, 2005). Some ethnic groups also have a greater distrust of healthcare providers than others (Valente & Haley, 2007). In addition, how “bad news” is communicated is also different from culture to culture (Searight & Gafford, 2005). Patients and family have the same right “not to know” as they have “to know” as the desire to tell or know the truth about illness or death may mainly be a Western cultural value (Pereira & Bruera, 2001, p. 67).

4.1.5 Tips for Advance Care Planning

Lastly, patients’ full participation is key to effectiveness of ACP (BC Renal Agency, 2009, p. 13). The BC Renal Agency (2009, p. 14) suggests that, to gauge a patient’s anticipated level of participation, consider patient’s ability to be involved in ACP, their interest in participating, their perception of level of control in healthcare decisions, perception of potential benefits of participating in ACP, resources to help patient participate, and persons with whom the patient prefers to engage in ACP. As well, patients who are lacking capacity will not be able to properly participate in ACP discussions; therefore, it is important to test the capacity of patients with cognitive impairment before ACP can take place (Department of Health, 2008, p. 38).

To help frontline staff facilitate a successful ACP conversation, there are a number of useful tips and guidelines from the UK (Royal College of Physicians, 2009, p. 5). These include having discussions in comfortable, unhurried surroundings; maximizing patient capacity by treating any transient condition(s) affecting communication and sensory function; using a step

by step approach and tools to advance care planning, taking into account factors which influence attitudes to ACP discussions; clarifying ambiguous terms used by the patient; looking out for cues that the patient wishes to end the discussion; summarizing and checking understanding with the patient; documenting the discussion (in writing or with audio-visual recording, and in the patient's medical record), and planning for a review to revisit the advance care plan. Clinicians should practice empathetic listening, affirm patients' self-worth, and maintain trust, honesty, promise keeping, confidentiality, and care (BC Renal Agency, 2009, p. 14). In addition, the National End-of-Life Care Strategy (2008, p. 65) in the UK also recommends that patient requests concerning refusal of life sustaining interventions should be discussed with a physician.

Lastly, it is also important to discuss the patient's values, beliefs, and preferences with substitute decision makers to promote shared understanding (BC Renal Agency, 2009, p. 14); invalidate the advance care plan if the patient behaves in a manner that is inconsistent with their original specifications; and ensure that patients should carry some form of notification which indicates that they have completed an advance care plan and how it can be accessed (Department of Health, 2008, p. 74).

4.2 Symptom Management

Renal patients are one of the most symptomatic groups of people living with chronic illnesses (Germain and McCarthy, 2004; Jablonski, 2007). They often have prolonged period of symptoms and low functional abilities often punctuated with exacerbating complications and sudden death (Noble, 2009). Moreover, the symptom burden of these patients and quality of

life impairment are similar to that of patients with terminal malignancy (Saini *et al.*, 2006). These symptoms are results of chronic uremia, co-morbidities, and RRT itself (Brown *et al.*, 2007). Symptoms of patients with ESRD can include pain, agitation/restlessness, pruritus, constipation, excessive respiratory tract secretion resulting in noisy breathing, dyspnea, nausea and/or vomiting, fatigue, anorexia, sleep disturbances, and sexual dysfunction (Saini *et al.*, 2006; Gravin & Chapman, 1995; Brown *et al.*, 2008). More than half of the patients undergoing dialysis experience fatigue, pruritus, and constipation, and more than 40% of them experience anorexia, pain and sleep disturbance (Murtagh *et al.*, 2007). As such, symptom management is a crucial part of palliative care for this patient population as symptoms that are not effectively managed often adversely affect the patient's quality of life (Jablonski, 2007). Clinicians need to have adequate knowledge of opioids and adjuvants to opioids for pharmacological pain management (BC Renal Agency, 2009, p. 18). A key consideration in managing the symptoms of patients with ESRD is the pharmacokinetic properties of drugs in the presence of reduced or absent GFR (Cohen *et al.*, 2006). Special consideration should also be given to the analgesic effect in the geriatric population (Cohen *et al.*, 2003).

4.2.1 Pain Management

The essentials of pain assessment include believing the patient's report of pain; assessing pain in its site, character, intensity, extent, relieving/aggravating factors, and temporal relationships; using a simple assessment tool such as a numerical scale of 1-10, and educating patients and caregivers at home on pain assessment and charting (BC Renal Agency, 2009, p. 18; Davison, 2005). The education piece around the goals of therapy, management

plan, and potential complications can also help minimize non-compliance (BC Renal Agency, 2009, p. 18). There should also be regular reassessment of pain intensity and response to treatment (Sedgewick *et al.*, 2010). Some pharmacological principles of end-of-life care in patients with ESRD include using regularly scheduled pain medications with as-needed medications added for breakthrough pain, not capping the provision of adequate analgesic based on fear of patient dependence, and using intravenous (IV) agents if patients have preexisting IV access (Cohen *et al.*, 2006; Sklar *et al.*, 1996). When it is not possible to completely eliminate pain, a more realistic goal would be to optimize pain relief and focus on disability issues to help patients become more functional in their daily activities (BC Renal Agency, 2009, p.17). In addition, an interdisciplinary team, including a consultation to a palliative care team or chronic pain clinic, should be utilized to manage “total pain”, which refers to any unmet needs of the patient that may aggravate pain, such as financial or spiritual aspects of a patient’s needs (BC Renal Agency, 2009, p. 18).

4.2.2 Non-pharmacological Interventions

The use of non-pharmacological interventions can also be beneficial in reducing pain (BC Renal Agency, 2009, p. 18). Physical therapy such as transcutaneous nerve stimulation, hot and cold therapy, exercise and neuromuscular massage can be used where appropriate (BC Renal Agency, 2009, p. 18). Since pain may also be associated with psychosocial symptoms, good morale, mood, and nutrition can increase the pain threshold and help the patient feel less pain (BC Renal Agency, 2009, p. 18). On the other hand, anxiety, depression, and fears decrease the pain threshold (BC Renal Agency, 2009, p. 18).

4.3 Psychosocial, Spiritual, and Supportive Care

Being diagnosed with ESRD is difficult for patients and their families as they confront harsh realities and choices they do not really know how to make (Jablonski, 2008). Families frequently express complex emotions and frank indecisiveness when faced with this situation (Badger, 2005). Patients on dialysis often question how long it can prolong their lives and whether it should be stopped when their conditions deteriorate significantly (Jablonski, 2008). For patients who have opted for conservative management, their caregivers can find diagnostic uncertainty difficult and feel abandoned as they attempt to manage complex medication regimens and dietary modifications (Noble, 2008). Other major end-of-life concerns of patients include fear of pain, loss of dignity, abandonment and fear of the unknown (Brown *et al.*, 2008). Therefore, psychosocial and spiritual support for patients and their family are essential components of the care pathway (Jablonski, 2008).

Patients cope with their diagnosis in various ways, such as denial, depression, anger, guilt, humour, crying, prayers, rationalization, and keeping busy (Pereire & Bruera, 2001, p. 67). As well, certain patients are more likely to have difficulties adjusting to a palliative diagnosis. These include patients who lack support from at least one loved person; have had previous unresolved loss or separation; have a history of early parental death or multiple losses; use or have used alcohol or drugs in excess; have a history of mental illness; express severe emotional reactions; lack optimism, self confidence, or assertiveness; or have poor communication or conflict in relationships with family or physician (Pereire & Bruera, 2001, p. 67).

4.3.1 Psychosocial Support

Psychosocial support refers to addressing the psychological and social problems associated with ESRD (Patel *et al.*, 2002). Each person is a part of a family or community unit and has emotional, social and spiritual needs (Department of Health, 2008, p. 76). As such, a large part of psychosocial support involves having peer support networks for patients, where they can talk to and be understood by another patient with the same illness (Jablonski, 2008). Peer mentoring by patients on dialysis who have developed a positive coping mechanism and have been trained in mentoring other patients have been an effective way to help patients newer to dialysis in adjusting to it (Perry *et al.*, 2003). The University of Michigan also has a peer counseling program for patients requiring end-of-life care (Poppel *et al.*, 2003). Other good practices of psychosocial care include home visits, telephone contact and support, and active palliative care liaison (Murtagh *et al.*, 2006).

4.3.2 Supportive Care

There are also a number of supportive care strategies that providers can use to enable patients to better handle the diagnosis and the condition. Providers can find out what has helped the patient cope in the past, things that are working now, and what the patient perceives would help him/her cope more effectively (Pereire & Bruera, 2001, p. 67). Helping patients express and understand emotions, and maintain or strengthen relationship with significant others are effective strategies as well (Pereire & Bruera, 2001, p. 67). In addition, provide should also facilitate empowerment through allowing patients choice and control and

helping them arrange affairs, make funeral arrangements, and find ways to keep their memory alive (Pereire & Bruera, 2001, p. 67).

4.3.3 Spiritual Care

The National Institute for Health and Clinical Excellence in the UK and the National End-of-Life Care Strategy in the UK have identified spiritual care to be an integral part of end-of-life care (McGuigan & Gilbert, 2009; Department of Health, 2008, p. 49). ‘The essence of spiritual care is “being present” for people as they confront suffering and struggle with spiritual questions’ through establishing a trusting and empathetic relationship (Pereire & Bruera, 2001, p. 67). Spiritual support involves recognizing that every person is unique and should be treated with dignity and respect and given the opportunity to express their hopes and what means the most to them (Department of Health, 2008, p. 76). Often, this means allowing people to discover their own way of making sense of what is happening to them and to express anger, guilt, sadness and reconciliation (Department of Health, 2008, p. 76). As well, association with particular cultural, ethnic or religious group can significantly influence a patient’s expression and understanding of the meaning of pain and suffering, beliefs about the cause and meaning of the illness, choice of healer and treatment regimen, attitude toward death and dying, beliefs about the afterlife and the value of human life and the body, and preference for death ritual, including preparation for burial and funeral practices or memorial services (Pereire & Bruera, 2001, p. 68).

For more religious aspects of spiritual care, the term “chaplaincy services” is deemed acceptable by the National End-of-Life Care Strategy in the UK as an inclusive term to indicate a

service that caters to all faiths and spiritual needs (Department of Health, 2008, p. 76). To enable a chaplain to provide the necessary support, he/she needs to be recognized as an essential part of the multidisciplinary team that cares for the end-of-life needs of the patient (Department of Health, 2008, p. 78). In general, healthcare providers caring for the dying and bereaved should have reasonable knowledge of various practices of different faith groups and seek support when they encounter situations where their knowledge is limited (Department of Health, 2008, p. 76). Providers should also be aware of the need and desire of patients or families for ritualistic actions at the end of life or during bereavement, even if they would not normally describe themselves as religious or spiritual (Department of Health, 2008, p. 77).

The Southeastern Ontario Palliative and End-of-Life Care Network (SEOPEOLCN) outlines some suggestions on non-religious forms of spiritual support, such as music-thanatology, which is a professional field that unites music and palliative care, where musical comfort is provided at the bedside of patients near the end of life (Music-Thanatology Association International, 2008; SEOPEOLCN, 2009). Poems and words of inspiration may also bring spiritual comfort to some patients (SEOPEOLCN, 2009).

4.3.4 Support for the Family

Spiritual or supportive care for the family of the patient is an important aspect of care as well. Some indicators of poor family adjustment to a palliative diagnosis of the patient include inability to function as a cohesive unit, lack of positive outside support or unwillingness to use it, closed communication, reluctance to openly express emotions, or little or no participation in the care of the patient (Pereire & Bruera, 2001, p. 67). Healthcare providers can help families

cope better by facilitating the expression and understanding of emotions, helping to strengthen the relationship and communication between family members and the patient, helping family members differentiate their needs from those of the patient and provide assistance in meeting those needs, facilitating understanding of medical information and access to needed resources, and supporting and being present with family members on physical, psychological and spiritual levels (Pereire & Bruera, 2001, p. 67).

4.4 Terminal Care

Statistically, a patient who chooses conservative management lives an average of 6.3 months (Smith *et al.*, 2003). A patient who has withdrawn from dialysis has an average time to death of 8 days (Chambers, 2004). These patients, as well as other renal patients who may face imminent death, require terminal care, which involves caring for and supporting patients in the dying phase. During this phase, patients need intensive holistic care physically, psychologically, socially and spiritually (Sedgewick *et al.*, 2010). The emphasis of care need to transition to relieving and anticipating symptoms, comfort care, and support for any spiritual or religious needs (Brown *et al.*, 2008).

Healthcare providers should, through on-going communication, continue to explore the patient's cultural and religious preferences, and thoughts and beliefs relating to dying and death to enable delivery of care that is in keeping with the patient's wishes (Sedgewick *et al.*, 2010). Family should be informed clearly of the imminent death and have their concerns and questions addressed (Sedgewick *et al.*, 2010, Brown *et al.*, 2008). If the death is occurring in a hospital, they should be allowed to stay with the patient and given privacy to say goodbyes and

prepare themselves (Sedgewick *et al.*, 2010, Brown *et al.*, 2008). If the patient wishes to die at home, palliative care teams should provide a support structure for the patient to do so if such arrangements are feasible (Brown *et al.*, 2008). In addition, providing support to the family and caregivers in the patient's last days also improves the quality of death (Brown *et al.*, 2008).

4.4.1 End-of-life Symptoms

End-of-life symptoms for renal patients include retained secretions, shortness of breath, agitation, nausea and vomiting, pain, pruritus, and thirst (Noble, 2008). It should also be noted that patients often have very individual trajectories to death with specific care requirements (Noble, 2008). Only essential drugs should be administered subcutaneously to control symptoms; as well, reassessments of symptoms and interventions should be made regularly to ensure adequate symptom control (Sedgewick *et al.*, 2010; Pellett, 2009). Family members and caregivers of patients dying at home need to know medication doses, titration and how to obtain medical supplies (Sedgewick *et al.*, 2010). In the UK, there are out-of-hours services to which the patient can be referred so that medication can be checked and symptoms control assessed (Sedgewick *et al.*, 2010).

4.4.2 The Concept of a “Good Death”

A “good death” is that is free of pain, peaceful, brief, with loved ones present, and in a place where the patient has chosen to die (Ellersharw & Ward, 2003; Germain *et al.*, 2007; Brown *et al.*, 2008; Noble, 2008). Dying is not only what the patient experiences but also what the family remembers (Haras, 2008). As such, preservation of the patient's dignity, easy access to palliative care, as well as access to bereavement support for family members are also key to

a “good death” (Germain *et al.*, 2007). The Dialysis Quality of Dying Apgar (QODA) is a useful tool that assesses the quality of death (Haras, 2008). It involves scoring in 5 domains, including pain, non-pain symptoms, advance care planning, peace and time; the higher the score, the better the quality of death (Haras, 2008). Some barriers to a “good death” include inadequate control of pain and other symptoms, emotion stress on patient and the family, insufficient attention to family dynamics, absent or inadequate patient and family education about end-of-life care and advance care planning, failure to address diversity concerning religion, ethnicity, and culture as they relate to life completion and closure (Moss, 2003).

4.4.3 Helping Families Prepare for End-of-Life

Families want information about what to expect during the dying process (Haras, 2008). During this time, they find it helpful to maintain honest and open communication from a consistent healthcare provider (Haras, 2008). Healthcare professionals can help families prepare for end-of-life through educating them on the indicators of imminent death, such as fluctuating levels of consciousness with gradual decline accompanied by decreased awareness, and reassuring them that the changes they will observe are usually more distressing for them than for the patient (Pereira & Bruera, 2001, p. 70). The Alberta Hospice Palliative Care Resource Manual (2001, p. 70) also provides some more suggestions: instruct family caregivers in symptom management and comfort measures, ensure family members have access to appropriate professional and support services and needed equipment and supplies, encourage family members to tell the patient what he/she meant to them and how he/she will be remembered even if the patient appears not to hear or respond, encourage families to give the patient permission to die and say their goodbyes, encourage fathering of

family and friends, encourage touching and grieving, and use role modeling to say the words that need to be said (e.g., “You will always be loved”) and to communicate non-verbally.

4.5 Bereavement Support

Bereavement is the state of having suffered the death of someone significant (Young, 2009). Anticipatory bereavement can be present before the patient actually dies; it can be experienced by the patient, their family, other patients and families in the unit, and by the healthcare providers caring for the patient (Casarett *et al.*, 2001). Berns and Colvin (1998) purport that “by understanding the importance of what family members report about the events of the death of their loved one, healthcare providers can improve the quality of end-of-life care”. For families, being present or absent at the death of the patient constitute a significant memory and keeping promises and wishes made to the loved one helps them cope with the loss of that person (Young, 2009). Families also feel that giving a patient the permission to die is a powerful directive that should be in their control (Haras, 2008). Moreover, it has been shown that the care and support offered by healthcare providers after the death of a patient can define how people cope with bereavement (Department of Health, 2005). When the bereavement process is not handled properly, surviving family members can become patients themselves in the healthcare system, burdens on society, and/or unproductive at work (Canadian Hospice Palliative Care Association, 2002).

4.5.1 When a Patient Dies

It may be practical for the renal team to use a bereavement checklist with the necessary steps that the team must go through when a patient dies (BC Renal Agency, 2009, p. 22). Some

immediate steps concern proper handling of the patient's body. When a patient has just passed away, timely verification and certification of death is key in reducing distress for the family (Department of Health, 2008, p. 68). If death has occurred in an institution, the body should to be handled and laid out in a way that is culturally sensitive and in keeping with the religious beliefs of the deceased and his/her family (Department of Health, 2008, p. 68). Similarly, organ donation discussions with family must respect their cultural and religious beliefs (Department of Health, 2008, p. 68). In addition, healthcare providers should contact relevant services to inform them of the death as getting appointment reminders for the deceased can be very distressing to the family (Department of Health, 2008, p. 68).

4.5.2 Support for the Family

More and more dialysis units and renal teams formally recognize the death of a patient, which has benefited the families, other patients as well as dialysis staff and/or the renal team (Holley, 2005). Aside from offering the family tissues and water, validating their feelings, providing emotional support (Archer, 2008), healthcare providers should also allow for silence if appropriate (since it's their presence that counts), encourage families to express their feelings or to talk about the deceased, ask the family if they would like time alone with the deceased or if they would like the provider to stay with them, ask the family if there is anything they feel needs to be done, and ascertain special requests regarding treatment of the body after death and honour them if possible (Pereira & Bruera, 2001, p. 70). If appropriate, providers can also share their memories of the deceased; however, it's often not helpful to say that they know how the families feel (Pereira & Bruera, 2001, p. 70). Providers also need to share with the family information on

the disposal of the body (cremation or burial) and local services such as community support, funeral directors, social and health services etc. (Department of Health, 2008, p. 68).

4.5.3 General Bereavement Support

Other bereavement support practices after a patient has passed away include displaying an obituary or a ritual such as placing a flower in the deceased patient's chair as notification of death, sending letters or condolence cards to survivors and attending the funeral, holding annual memorial services (Holley, 2005). The End-of-Life Care Strategy in the UK (2008, p. 77) supports the provision of occasions and rituals, such as memorial services, for remembrance. At these events, information about bereavement support should be made available in case people want to self refer to bereavement services (Department of Health, 2008, p. 78). Other spiritual support for the bereaved, such as prayers in accordance with the family's preferred religion, readings about grief and life after death of a loved one, stories of hope and comfort collected by funeral services, and end-of-life poetry are often found in the local community and can also be helpful in meeting the spiritual and emotional needs following the loss of a loved one (SEOPEOLCN, 2009).

Lastly, it's also important to address staff's feelings and to create opportunities where they can discuss and reflect upon patients who have recently passed away in a respectful and non-judgmental environment (BC Renal Agency, 2009, p. 22). If there are bereavement and counseling services through, for example, employee assistance programs, staff should be made aware of that (BC Renal Agency, 2009, p. 22).

5. Palliative Care in Acute Care Settings

For the purpose of this section, acute care includes pre-dialysis clinics, dialysis clinics, and hospitals. Most literature specifically point to the formation of an interdisciplinary palliative care team within acute care settings as a good practice (e.g. Frey Steinson, 2010). One of the primary functions of the palliative care team is to facilitate the transition of care from the acute setting to the preferred site of end-of-life care and death for the patient (Meier & Beresford, 2008). Brown *et al.* (2008) from the UK suggest that, realistically, core patient care is still provided by the renal team with specialist palliative care consultation and advice as clinically necessary and available. Alternatively, one model in the UK involves having joint renal and palliative care clinics which provide better rapport-building and symptom control for patients rather than merely when the patient is near death (Germain & Cohen, 2007).

5.1 Best Practices

The literature has identified a large number of best practices for palliative care in acute care settings. First, the organization needs to establish an open culture that discusses death, palliative care, and supportive care during pre-dialysis meetings with patients (Sedgewick *et al.*, 2010). Second, the core care team should include the patient, other people that the patient wishes to be included in their care, healthcare providers in charge of the care of the patient, an ethics representative, and a member of the palliative care consult team (Archer, 2008). Some models include social workers and spiritual advisors as part of the core care team while others include them as part of the palliative care team (Archer, 2008).

The core team should have regular meetings to facilitate communication (Archer, 2008). Palliative care specialists need to be included in these meetings as well (Sedgewick *et al.*, 2010). Formal meetings should be held in the patient's room and documented (Archer, 2008). At these meetings, begin with introductions; make sure that everyone is on the same page; explain the clinical situation and prognosis; review the therapeutic plan, discuss end-of-life topics; support the family's responses and include a wrap-up session (Archer, 2008). The team should also have preparative communications with community services as needed, such as hospices (Sedgewick *et al.*, 2010). Interpreters should be made easily available if needed, and a small cohort of them who have become skilled in the necessary discussions should be used (Sedgewick *et al.*, 2010).

When a patient has passed away, there should be a critical care debriefing of the whole core renal care team (Sedgewick *et al.*, 2010). In addition, a scoring system can be used to rate the degree to which the death was a "good death" (Germain & Cohen, 2007). The team should examine whether the patient had advance care plans, whether their wishes were followed, the location of death, and whether dialysis was withdrawn before death if the patient was on dialysis (Germain & Cohen, 2007). If dialysis was not terminated, the team should look into the specific circumstances that resulted in this (Germain & Cohen, 2007).

6. Hospice Care

Hospice palliative care "aims to relieve suffering and improve the quality of living and dying (Canadian Hospice Palliative Care Association, 2002, p. 17). Specifically, it strives to help patients and families address physical, psychological, social, spiritual and practical issues, and

their associated expectations, needs hopes and fears; prepare for and manage self-determined life closure and the dying process; and cope with loss and grief during the illness and bereavement (Canadian Hospice Palliative Care Association, 2002, p. 17). As well, hospice care focuses on palliating symptoms, and may complement disease-modifying therapy or become the entire focus of care (Midson & Carter, 2010; Canadian Hospice Palliative Care Association, 2002, p. 17). Thus, timely referral to hospice care is essential and requires close collaboration among care providers (Sedgewick *et al.*, 2010). Composition of care teams in hospices vary from place to place. In Quebec, the core caregivers in hospices include physicians, nurses, social workers, pastoral associates, and sometimes client care attendants (Ministry of Health and Aging, n.d. p. 28). The use of volunteers also increases overall satisfaction of hospice services (Alspach, 2010; Ministry of Health and Aging, n.d. p. 28).

6.1 From a Family Member's Perspective

In an editorial from *Critical Care Nurse* by Alspach (2010), one family member wrote about what is good practice from her personal experience. Upon the family's arrival, they were introduced to all staff involved in the care of their loved one, given an update on the patient's condition, and interviewed for priorities and preferences. All aspects of care were dictated first by the patient's preferences. A blend of traditional and alternative health interventions were available to suit patient and family preferences. Full support services were available to make the family feel comfortable at the hospice. There was openness about information sharing and the healthcare team involved the patient and family into a partnership with them. The care team was sensitive in inquiries about, for example, any issue that family may or may not want

to hear about; they were non-judgmental and never assumed any religious preferences but always clarified with the patient and family. Furthermore, the team always strived to improve the patient's experiences through various quality improvement initiatives.

6.2 Models of Hospice Care

Currently, there are a number of models of hospice care. In the UK, one model involves the partnering of hospice palliative care nurse specialists with community matrons, who are experienced nurses competent to provide advanced nursing and clinical care in the patient's home (Freysteinson, 2010). In Memorial Hermann Home Health Hospice in Houston, US, multidisciplinary teams, composed of a palliative care physician, a palliative care nurse practitioner, registered nurses, social workers and therapists provide home visits to palliate physical and emotional sufferings (Alsop, 2010). One study showed that palliative care in the patient's home can significantly improve patient and family satisfaction, result in fewer emergency department visits, lower medical costs, and increase deaths at home (which is the preferred place to die for most patients) (Alsop, 2010).

There are also partnerships between hospices and hospitals in the US, where hospices provide palliative care education for hospital staff, inpatient hospice beds, and bereavement services for families (Freysteinson, 2010). This is an effective partnership since not all patient needs are met with hospices and some patients don't want to go to hospices (Freysteinson, 2010). For example, in Denver, the hospice is partnered with 8 hospitals and sends a palliative care physician and/or nurse practitioner to the hospitals to provide care; they also provide follow-up visits when the patients are discharged from the hospital (Meier & Beresford, 2007).

7. Education

Educational for patients and families as well as healthcare providers is an important element of palliative care programs (Jablonski, 2008) and can address system misconceptions of end-of-life care. Some examples of such misconceptions include equating palliative and hospice care and thinking that only patients who are near the end-of-life are appropriate candidates for palliative care; thinking that a chronic illness alone does not qualify a patient for palliative care services; as well as deeming patients with ESRD not appropriate candidates for palliative care because they often live for years on renal replacement therapy (Jablonski, 2008).

7.1 Patient and Family Education

For patient and family education, a simple folder with all the information and resources they may need can be useful (Archer, 2008). The End-of-Life Care Strategy (2008) in the UK recommends a similar one-stop-shop to all the information patients and families need in terms of condition specific support, financial support and benefits, employment support, support that is available to both the patient and caregivers, practical advice to what to do when someone died and bereavement support (Department of Health, 2008, p. 75). Peer education for patients through expert patients should also be included (Department of Health, 2008, p. 75).

7.2 Staff Education

Some essential knowledge and core competencies that healthcare providers providing end-of-life care need to possess include communication in end-of-life discussions, assessment of the physical, emotional and spiritual needs of the patients, advance care planning, symptom

management and maintaining patient comfort and wellbeing (Henry & Hayes, 2010). The UK has a document titled “Common core competences and principles for health and social care workers working with adults at the end-of-life” which contains a more complete list of skills and competencies required for end-of-life care.

Many renal or palliative programs have their own educational initiatives that help staff to be more competent and to provide better care (e.g., McGuigan & Gilbert, 2009). However, Levy *et al.* (2004) also advocate for joint educational programs for core care teams, such as the renal team, and the palliative care team. In addition, Palliative Care Australia supports end-of-life care education for primary care providers in terms of training for advance care planning and end-of-life discussions and care (Palliative Care Australia, n.d., p. 2).

7.2.1 Guidelines and Strategies for Staff Education

Training for staff should be workplace-based, recurrent, and led by experts and expert patients (Royal College of Physicians, 2009). Education cannot rely on mere distribution of education materials, although they can be complimentary in training sessions (Royal College of Physicians, 2009). The End-of-Life Care Strategy from the BC Provincial Renal Agency (2009) advocate the use of champions trained by recognized palliative and renal experts to facilitate local training. The training and education is based on current research evidence with a focus on increasing knowledge in patient risk identification, advance care planning, symptom assessment and management, and care of the dying patient and bereavement (BC Renal Agency, 2009, p 24). Part of their education strategy also include ensuring that end-of-life educational programs and resources are available and continuously updated on Renal Agency website, using exiting

opportunities such as the BC Nephrology Days to provide ongoing training, and using pilot projects to demonstrate the benefits of such training (BC Renal Agency, 2009, p. 23). The Renal Agency also recommends that end-of-life guidelines should be standardized across the province to ensure the consistency of service at various locations (BC Renal Agency, 2009, p. 24). Part of the champions' role is to facilitate the integration of this guideline at the local level into the ongoing work of renal staff (BC Renal Agency, 2009, p. 24).

8. Recommendations

Based on the review of literature and frameworks in this report as well as the current practices in palliative care in Nova Scotia, the following recommendations are made for the Nova Scotia Renal Program on the provision of palliative care services for patients with ESRD.

1. All healthcare providers involved in palliative care, including renal physicians and nurses as well as primary care physicians, should participate in palliative care education and possess the necessary skill set to provide such care (Levy *et al.*, 2004; Germain and Cohen, 2007). The "Common core competences and principles for health and social care workers working with adults at the end-of-life" document in the UK can be consulted for this purpose.
2. Patients should be referred and have access to palliative care and related support at the diagnosis of ESRD, as most literature suggests. As such, palliative care programs should not only provide service to those who are anticipated to die within 12 months because palliative care is not merely end-of-life care. Furthermore, there needs to be clear and

standardized criteria for referrals to palliative care and to hospice beds or hospices so that patients can be referred upon diagnosis and that they will not slip through the gap and not receive care or receive it too late when it is needed.

3. The Nova Scotia Renal Program needs to develop a provincial framework for palliative care for renal patients to guide service delivery across the province and minimize disparities in the care that is provided. The framework should adopt the best practices that have been described in this report as part of the guidelines on the components of palliative care, including advance care planning, symptom management, psychosocial, supportive and spiritual care, terminal care and bereavement support.
4. The Nova Scotia Renal Program should also explore various partnerships and creative ways to overcome resource and budgetary constraints. For example, hospitals can partner up with hospices, where hospice staff who are specialists in palliative care can help to educate and train hospital healthcare providers who care for patients who may be near the end-of-life on a regular basis. Such partnership can also expand home palliative care services, which has been demonstrated to increase patient and family satisfaction, reduce emergency department visits, and decrease medical costs. Out-of-hours specialist palliative care services can also be expanded. Similar arrangements can be made with other palliative care supports in the community, such as with VON.

Conclusion

Although many jurisdictions both outside and in Canada have established palliative care programs and frameworks to support the service delivery of these programs, palliative care for

renal patients in specific still tends to be overlooked, with the majority of attention given to the area only found in academic literature. Therefore, the Nova Scotia Renal Program is in a unique position with the opportunity to be one of the first jurisdictions to have a palliative or end-of-life care focus in the provision of health services to patients with advanced and incurable renal conditions. Implementation of the best practices of renal palliative care outlined in this report as well as the rest of the recommendations will minimize the number of renal patients with palliative care needs but are not accessing or cannot access palliative care and improve the quality of palliative care for this patient population across the province.

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Appendix A – Limitations

Due to the time restraints, this review has not addressed all the pertinent issues in end-of-life care for patients with ESRD. Some topics not addressed here include pediatric palliative care, detailed symptom management and pharmaceutical information, ethical and legal issues relating to end of life care and withdrawing or withholding life-saving interventions, self care, home care and care in the community or long term care facilities for patients with ESRD, and evaluative methods to assess palliative care programs for patients with ESRD.

In addition, it was not possible, within the time given to prepare this report, to interview people who are involved in renal palliative care in other provinces to draw on their expert knowledge in this field.

A number of articles and frameworks that were used in this report are from the UK, the US, Ireland, New Zealand, and Australia, which may have limited applicability to the Canadian context due to differences in health system structures, culture, and funding availability.

Appendix B – Term Definitions

Palliative care: improving the quality of life of patients suffering from life-limiting illnesses and their families through meeting their needs on physical, emotional and psychological levels (WHO, 2011). Palliative care can overlap with curative treatments as well (Reiter & Chambers, 2004; Nobel *et al.*, 2005; Holley, 2006; Sedgewick *et al.*, 2010).

End-of-life care: services provided to patients with advanced, progressive and incurable illnesses, such as ESRD, to enable them to live as well as possible until death (Masalmeh, 2009).

As shown in *Figure 1* below, end-of-life care is part of overall palliative care services.

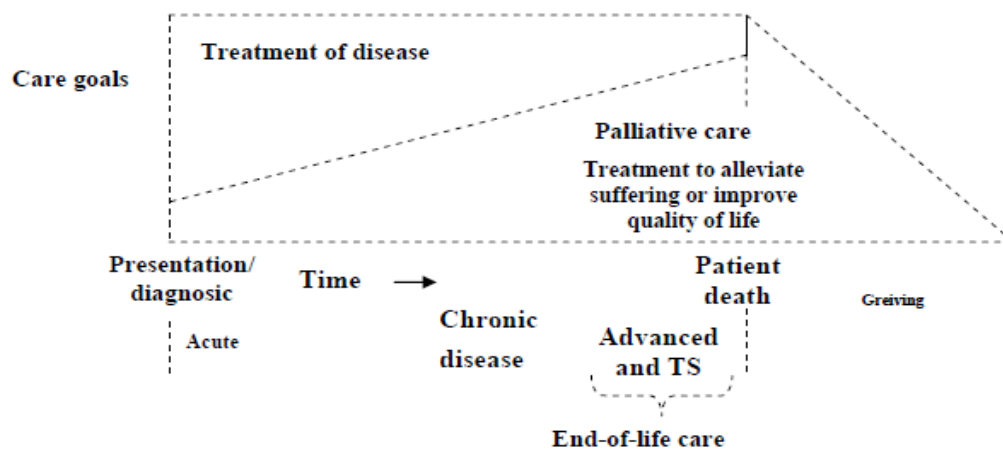


Figure 1. A conceptualization of the treatment of disease, palliative care, and end-of-life Care (Quebec End-of-Life Palliative Care Policy, n.d.).

Terminal care: care provided to the patient in the last days or weeks of the patient's life, which largely involves focusing on comfort care and symptom management, as well as allowing the family to say their goodbyes.

Conservative management: care provided to patients who have an ESRD diagnosis but decided not to initiate dialysis or go through kidney transplantation for various personal reasons.

These patients have an average of 6.3 months to live (Smith *et al.*, 2003) and therefore have urgent palliative care needs.

Supportive care: the non-medical aspect of helping patients cope with an ESRD diagnosis, such as helping patients to express and understand emotions and facilitating patient empowerment through giving patients choice and control (Pereira & Bruera, 2001). It may also include helping patients with the financial aspect of management their health care.

Spiritual care: services that address spiritual needs of patients, which can vary widely among individuals. For some patients, it involves having a healthcare provider being there for them as they explore the meaning of what is happening to them (Department of Health, 2008). For other patients, spiritual care may be a way to help them delve deeper into their faiths.

Specialist palliative care: palliative care services provided by healthcare providers who have received full training in palliative care and work specifically with patients with palliative care needs (e.g., physicians who specialize in palliative care).

Non-specialist palliative care: palliative care services provided by healthcare providers who are not specialized in palliative care but may have received some form of palliative care education or training.

Appendix C – Methods

Three search engines were used to gather academic articles for review for this report. Medical Subject Heading (MeSH) search terms used in PubMed included “kidney”, “kidney failure, chronic”, and “palliative care”. Key words used in CINAHL and Embase (which includes MEDLINE) were “renal” and/or “palliative care”. Articles no older than 2005 and published in English were then selected by the author based on relevance to the topic of this report.

In addition, palliative care and renal services websites of a wide range of jurisdictions, such as the UK, Australia, New Zealand, Ireland, British Columbia, Alberta, Ontario, and Quebec, were also hand-searched for frameworks and relevant documents. Google was also used with search terms “end-of-life care renal disease” and “renal palliative care” to ensure that no useful frameworks or documents are left out of this report.

The author also interviewed key informants (see Acknowledgement) in order to explore the current state of palliative care services for patients with chronic renal conditions in Nova Scotia.

Appendix D – Barriers in Palliative Care

General Barriers in Palliative Care

There are numerous barriers to palliative care and being aware of them will enable healthcare professionals to better meet the needs of these patients. Studies show that when physicians and nurses are preoccupied with active treatment and negative perceptions of palliative care, they may be reluctant to be open in their communication with patients about death, which prevents patients and their families from fully participating in care choices (Gott *et al.*, 2009). As well, inadequate understanding of what hope means to the patient can also hamper care. For example, to healthcare providers, discontinuing active treatment of the illness or being completely honest with patients and families about prognosis may seem to “take away hope”; however, hope is actually a “dynamic concept and is real even for patients at the end of life” (Mahon, 2010). Patients at the end of life may not have the hope for a cure, but can still express hope for living the remainder of their days well, for a death without suffering, for good lives for their family, and more (Mahon, 2010). Other barriers include healthcare providers not knowing which patients to refer to palliative care or when, physicians’ unwillingness to “hand over” or “share” patients, misconceptions such as palliative care is only for cancer patients, and resistance from patients and families because of perceived association between palliative care and imminent death (Ahmed *et al.*, 2004).

Specific Barriers to Advance Care Planning

A number of communication barriers have been identified, and healthcare providers can improve the quality of advance care planning for patients by avoiding these barriers. First, healthcare providers can avoid false hope and confusion if they directly use terms such as death and dying (Royak-Schaler *et al.*, 2006). Second, healthcare providers need to be open and honest with patients as the majority of patients prefer to know their prognosis and feel empowered when making end of life decisions (Heyland *et al.*, 2003). Keeping the truth, however discouraging, from the patient can often cause more anxiety and also directly prevent the patient from participating in crucial end of life discussions (Costello, 2001). Other barriers to healthcare providers include limited time to engage in ACP, lack of consensus on when to start ACP conversations and who to include, lack of professional training and resources, personal discomfort with the subject, conflicting views between patients and providers, and concerns that initiating ACP discussions could destroy hope for patients. Barriers for patients and family include a lack of understanding regarding prognosis, unrealistic patients and family expectations, and a reluctance to broach end of life discussions (BC Renal Agency, 2009).

Barriers to Quality Palliative Care in Acute Care Settings

The End of Life Care Strategy (2008) in the UK identified some barriers to the provision of good end of life care in acute care settings. First, hospitals may fail to recognize the providing care for patients at the end of their life is one of the core roles of an acute care hospital and fail to take responsibility in enabling people to return home to die if that's their wish (Department of Health, 2008). As well, a lack of leadership from senior managers and clinicians in patients'

palliative care needs can hamper care (Department of Health, 2008). Lastly, frontline staff may not have the necessary knowledge, skills and attitudes that are required to deliver quality end of life care; specifically, they may not recognize when continuing treatment is not in the patient's best interest and therefore miss the opportunity to provide more holistic care (Department of Health, 2008).

Appendix E – Toolbox

Tools for Advance Care Planning

There are a number of tools available for advance care planning since it's often difficult for patients and providers to initiate the conversation for end-of-life care preferences (Lankarani-Fard et al, 2009). Patients may be unclear about their priorities and preferences or too emotional or fragile to engage in the discussion (Lankarani-Fard et al, 2009). It's also difficult to predict which issues are going to be important in the future of the patient's medical care (Lankarani-Fard et al, 2009).

- The Preferred Priorities for Care, recommended by the National Services Framework for Renal Services as well as the National End of Life Care Strategy in the UK, is a document that patients hold on to and take with them as they receive care in various healthcare settings (Greaves *et al.*, 2009). It contains information on the patient's thoughts about their end-of-life care that he/she has filled out, including where they want to be when they die (Greaves *et al.*, 2009).
- The go wish card game can also accurately capture and reflect patients' priorities in an efficient manner (Lankarani-Fard et al, 2009). It consists of 35 cards each marked with a single value, such as to be free from pain, and a wild card to which patients can assign their own value (Lankarani-Fard et al, 2009).
- The ACP readiness instrument can assess whether patients are ready for advance care planning or general end of life conversations (Haras, 2009). Calvin and Eriksen (2006) suggest that one of the reasons why advance directives have low completion rates is

that providers have not assessed whether a patient is ready to discuss such issues (Haras, 2008). However, should a patient express an unwillingness to address their own mortality, that wish should be respected (Department of Health, 2008).

- In BC, the Fraser Health Authority has developed its Advance Care Planning tools based on the “Respecting Choices Advance Care Planning System” offered by Gundersen Lutheran Medical Foundation in the US, and is available on the Fraser Health website (BC Renal Agency, 2009).
- In Alberta, advance care planning is facilitated by “My Voice”, which is a workbook that helps the person consider (and contains information on) substitute decision makers, the type of treatment that the person wants considered, the type of treatment that the person would not want considered, the person’s wishes for end-of-life experience, and the values that the person would want to guide significant decisions (Calgary Health Region, 2010). This tool (found [here](#)) is also endorsed by the Southeastern Ontario Palliative and End-of-Life Care Network following successful implementation at the Prince Edward Family Health Team in Picton, Ontario (SEOPEOLCN, 2009).

Tools for Pain and Symptom Management

The National Liverpool Care Pathway Renal Symptom Control Guidelines in the UK as well as the UK Expert Consensus Group’s evidence-based guidelines for pain and symptom management in adults dying from ESRD contain detailed information on this topic. In pain management, clinicians have also found the WHO three-step analgesic ladder to be effective for

adults with ESRD (Fassett *et al.*, 2011). Numerous articles in the palliative care literature provide guidance on pain management for end-of-life care as well (e.g. Murtagh *et al.*, 2006).

The Edmonton Symptom Assessment System (ESAS) was originally developed by the Regional Palliative Care Program in Capital Health in Edmonton (Cancer Care Ontario, 2003a). It is designed to assess pain, tiredness, nausea, depression, anxiety, drowsiness, appetite, well being, and shortness of breath (Cancer Care Ontario, 2003a). The patient would circle the level that corresponds to their condition on a numerical scale of 1 to 10 (e.g., 1 being no pain, and 10 being the worst possible pain). Regular symptom assessment with relevant tools such as the Edmonton Symptom Assessment System (ESAS) modified for use in renal care should be adopted (Davison *et al.*, 2006). This tool can be accessed [here](#).

The Palliative Performance Scale (PPS) is a tool developed by Victoria Hospice Society, BC, and guides the assessment of a patient's functional performance (Cancer Care Ontario, 2003b). The tool is divided into 11 categories measured in 10% decremental (i.e. 100% to 0%) stages and classified into 3 stages: stable, transitional, and end-of-life. The 5 observable parameters included in the functional assessment are degree of ambulation, ability to do activities, ability to do self-care, intake, and level of consciousness (Cancer Care Ontario, 2003b). This tool is completed by a healthcare professional. This tool can be accessed [here](#).

The Memorial Symptom Assessment Scale (MSAS) is a patient rated instrument that is also aimed at assessing numerous symptoms, such as pain, lack of energy, and nausea. It assesses whether the patient experiences the symptom as well as the frequency and severity of the symptom. This tool can be accessed [here](#).

Established Educational Curriculums and Programs

The Robert Wood Johnson Foundation's Workgroup on ESRD has developed a core curriculum in palliative care that was published in 2004 and encouraged its incorporation into renal training programs (Germain & Cohen, 2007). The curriculum include topics such as inclusion of a palliative care focus into dialysis units, teaching good patients and family communication techniques, ethical issues, surrounding withholding or withdrawing from dialysis, advance care planning, pain and symptom management, hospice care, and bereavement support (Germain & Cohen, 2007).

The Teenage Cancer Trust in the UK has a three-day, self-directed training program with eight modules that is aimed to develop providers' knowledge, skills, understanding, and self-awareness to meet the needs of dying patients and family (McGuigan & Gilbert, 2009). The modules include communication skills in bereavement, understanding loss, reactions to bereavement, legal and professional aspects of death in hospital, attending to the practical issues of a patient who dies in hospital, cultural and spiritual diversity issues, providing support and information for the bereaved, and healthcare professionals' self-care (McGuigan & Gilbert, 2009).

As well, the End of Life Care Strategy (2008) in the UK has recommended end-of-life care e-learning, which is a learning package that is made available to providers in the acute care, community care and mental health sectors (Glasper, 2010).

Appendix F – “Do-Not-Resuscitate” (DNR) Orders

According to the Alberta Hospice Palliative Care Resource Manual (2001, p. 69), the decision concerning resuscitation status should be based on the extent of the illness of the patient, the quality of life, potential causes of cardiac or respiratory arrest, and patient and family preferences. When approaching such discussions, healthcare providers are encouraged to first explore the patient’s and his/her family’s understanding of the illness and the prognosis and correct any misconceptions; emphasize the goals of palliative care, such as providing comfort, alleviating suffering, enhancing the quality of life, and promoting a peaceful death; and reassure patients and family that a DNR order does not mean that all treatment ceases (Pereira and Bruera, 2001, p. 70). Lastly, healthcare providers should explain that if the patient’s illness progresses to the point where breathing stops or the heart stops beating, resuscitations efforts are not recommended as it usually results in needless suffering for patients and families (Pereira and Bruera, 2001, p. 70).