

# Transitions in the lives of patients with End Stage Renal Disease: a cause of suffering and an opportunity for healing

**Tom A Hutchinson** Division of Palliative Medicine, Department of Medicine, McGill University Health Centre, Programs in Integrated Whole Person Care and Department of Oncology, McGill University, Montreal, Quebec

The treatment of End Stage Renal Disease (ESRD) successfully prolongs the survival of patients with kidney disease but requires that ESRD patients cope with frequent deleterious changes in their health and life situation, and shortened survival. Although the nephrology team is well-equipped to deal with the medical and technical aspects of care, it is less well-equipped to help patients with the impact of the difficult human transitions that come with dialysis and transplant treatment. Times of great challenge can also be opportunities for personal growth and healing but this often requires outside support. We need to develop new resources specifically aimed at helping ESRD patients complete important life transitions and more research on the frequency and impact of these events. *Palliative Medicine* 2005; 19: 270–277

## Background

Although treatment for End Stage Renal Disease (ESRD) prolongs the survival of patients with kidney failure, it does not, in most cases, return the lives of these patients to their state of health prior to illness. For patients on haemodialysis there are the challenges of regular dialysis treatments, residual uremic symptoms, complications of underlying diseases, vascular access problems and a shortened life expectancy.<sup>1</sup> Starting dialysis treatment amounts to embarking on a completely new way of life that challenges the patient's coping mechanisms and involves a re-evaluation of their identity. This daunting re-evaluation process is repeated as patients face other major transitions in the ESRD trajectory. While nephrologists are generally well aware of the biomedical challenges of renal failure and dialysis, they may be less aware of the subjective internal processes that are required to adjust to the many phases of ESRD treatment. Helping patients handle these challenges is an essential part of patient care, if optimal quality of life is recognized as a therapeutic goal. The task is to help patients successfully negotiate the difficult transitions that accompany life on ESRD treatment.

Address for correspondence: Tom A. Hutchinson, McGill Programs in Integrated Whole Person Care, Department of Oncology, McGill University, 546 Pine Ave. West, Room 301, Montreal, QC H2W 1S6 Canada.  
Email: tom.hutchinson@mcgill.ca

© 2005 Edward Arnold (Publishers) Ltd

## Narrative

The experience of a teenage boy facing his first dialysis is instructive.<sup>2</sup>

When I was in grade 11 they told me I should go visit a dialysis unit now because my creatinine was getting too high. My mother made an appointment for me to go see the dialysis unit. My mother took me out to lunch for pizza nearby, and then we visited the unit. We walked into the unit and all I saw was old people, and they looked terrible. I was thinking to myself, "This is what I am going in for?" I left very quickly and as soon as I got outside I threw up all over the sidewalk. I guess I was a little more upset than I thought. So I blocked the whole thing out of my mind, graduated from high school and started college... I was 19 when my doctor called me and said it was time to start dialysis. I told him, "No, I don't think so, it's not for me." He said, "What do you mean, what are you talking about?" I told him again, "It's not for me, it's not my lifestyle." He then told me if I did not start I would die in a few weeks. I told him that was fine, I'd had a good life.

## Transitions in ESRD treatment

Despite his protestations, the young man described above did start dialysis, but one gets some sense of the

10.1191/0269216305pm1028oa

magnitude of the disruption that this represented for him. He then went on to have a kidney transplant that eventually failed, followed by severe vascular access problems and a second emergency kidney transplant that was still functioning at the time his story was written.<sup>2</sup> Like many patients with kidney failure, he faced not one, but multiple challenging transitions. Table 1 lists some common transitions in patients with kidney failure. Each of these transitions poses a threat to the patient's world view and requires a multifaceted adjustment and reorientation to deal with it effectively.

## Negotiating life transitions

ESRD patients are not alone in their need to negotiate important transitions. We know a lot about this process from psychology and even mythology. Family therapist Virginia Satir called this psychodynamic adaptation 'the change process';<sup>3</sup> liaison psychiatrist Collin Murray Parkes referred to it as 'negotiating a psychosocial transition';<sup>4</sup> narrative therapist Michael White speaks of a 'migration of identity'<sup>5</sup> and mythologist Joseph Campbell wrote of 'the hero's journey'.<sup>6</sup> The adaptation processes described by these scholars are remarkably similar. For example, they all agree that in the middle of this process there is a very difficult period before the person can experience a successful resolution. This period has been described as 'chaos' (Satir); 'the phase of disorganization and despair' (Parkes); 'the liminal or betwixt and between space when confusion and disorientation reigns' (White); and 'the Belly of the Whale' (Campbell). White provides a depiction of the emotional adaptation to change experienced by a woman leaving an abusive relationship (Figure 1).<sup>5</sup> As can be seen from the graph, the woman's sense of

wellbeing rises just before the separation, only to plummet very soon afterwards. Her wellbeing takes almost a year to return to levels close to that at the point of separation. Is there evidence that our patients on treatment for ESRD experience a similar migration of identity and associated internal upheaval? If so, what implications does this have for the care of patients on ESRD treatment?

## Evidence that ESRD patients experience "migrations of identity" and an associated adaptation demand

The best evidence that ESRD patients do experience 'migrations of identity' comes from a qualitative study based on in-depth interviews of 36 patients on dialysis treatment at one hospital.<sup>7</sup> The interviews were interpreted using grounded theory and three major constructs were identified as: redefinition of self; quality of supports; and meanings of illness and treatment. To quote from that paper: 'The early weeks and months were marked by periods of emotional upheaval and doubts about the future.' The subjective feelings of patients were similar to those depicted in Figure 1 and to those of people undergoing other major transitions in life: the image of low self-worth was captured in descriptors such as 'helplessness, dependence, humiliation, and inadequacy.' Although it is obvious that the first construct, 'redefinition of self', concerns a change of identity, in fact, it appears that all three major constructs identified in this study relate to the individual's struggle to come to terms with a new world in which their relationships to self, to others and to their health and treatment have changed in a profound way. Similar evidence that ESRD patients face profound internal psychological changes can be found in published narratives of ESRD patient experiences.<sup>2,8</sup>

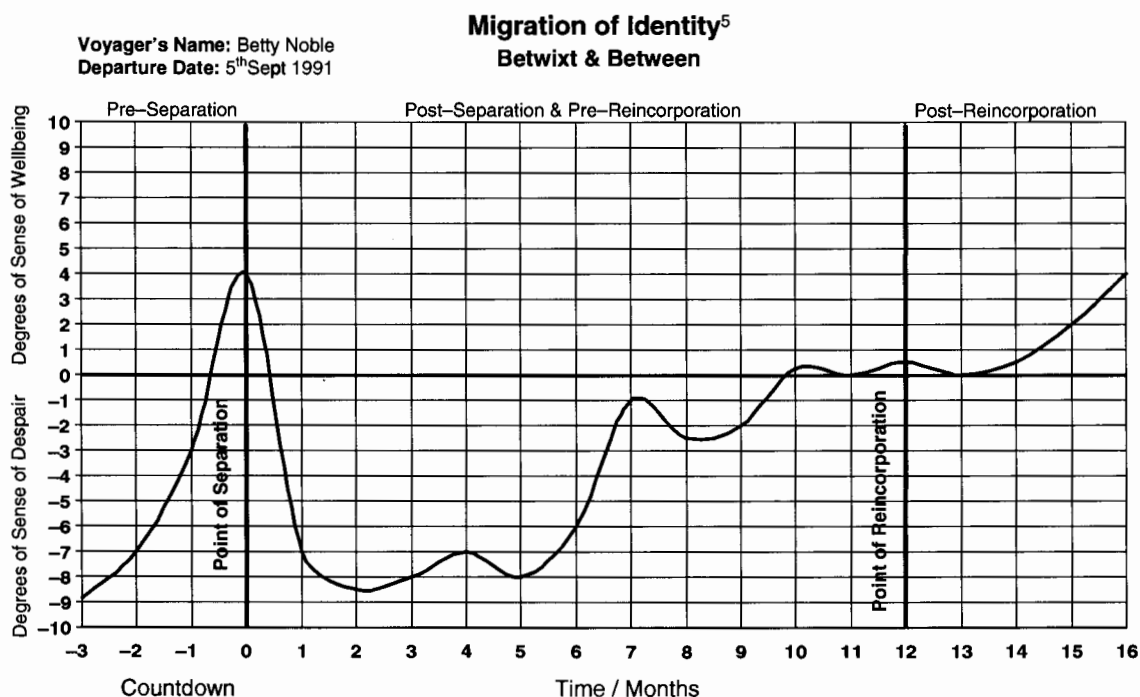
**Table 1**

### Major transitions in the lives of ESRD patients

Diagnosis of renal disease
Diagnosis of progression; ESRD inevitable
Obtaining vascular or peritoneal access
Starting dialysis treatment
Change to a different dialysis modality
Receiving a kidney transplant
Failure of vascular or peritoneal access
Failure of a kidney transplant and return to dialysis
Major medical complication
Loss of function (e.g., loss of a limb, loss of vision, decreased function due to cardiac dysfunction)
Loss of employment
Change in living arrangements (e.g., transfer to a nursing home or long-term care facility)
Death of another patient with whom a relationship has developed
Decision to stop dialysis
Impending death

## High mortality

Although dialysis and transplantation are highly effective treatments in preventing immediate death from renal failure these treatments do not return the patients' life expectancy to that of the general population. Figure 2 compares mortality for men aged 35–65 undergoing ESRD treatment with that of the general population and patients with various cancers.<sup>1</sup> ESRD patients on treatment have a mortality similar to that of prostate and colon cancer. This creates three challenges:

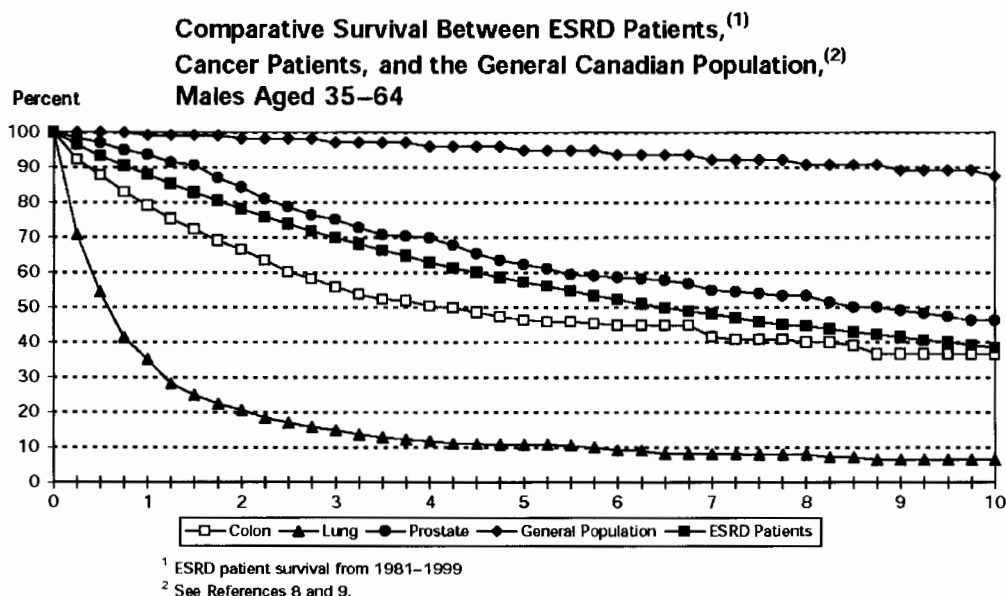


**Figure 1** Time course of changes in QOL in a woman leaving an abusive relationship.<sup>5</sup>

- 1) the time that ESRD patients have to adjust to difficult life transitions may be limited;
- 2) the deaths of other patients are a frequent experience challenging surviving patients with multiple losses; and
- 3) the ESRD patients' own impending death is a constant threat at a conscious or subconscious level.<sup>9</sup>

### Coping

With the very challenging, inherent risks of ESRD treatment outlined above (frequent difficult transitions and high mortality), it is reasonable to ask how patients cope. We believe that they use the inherent human ability to grow and change in the face of difficult challenges.



**Figure 2** Comparison of the survival of ESRD patients with the survival of cancer patients and of the general population.

Each of the authors mentioned above (Satir, Parkes, White and Campbell) describe the completion of adaptation to major psychosocial transitions using different language. For Satir it is 'integration',<sup>3</sup> for Parkes it is 'gaining a new identity',<sup>4</sup> for White it is 'reincorporation',<sup>5</sup> and for Campbell it is 'the return of the hero'.<sup>6</sup> Failure to complete the process leads to continued suffering.

### The nature of suffering

Eric Cassell clarifies the nature of suffering in a landmark paper<sup>10</sup> and subsequent book.<sup>11</sup> Suffering is not pain, or shortness of breath or loss of function, although it can be triggered by any of those things. Cassell makes three main points.<sup>10</sup> Suffering is experienced by whole persons. It occurs when an impending destruction of the person is perceived and continues until the threat has passed or the person has found another way to achieve a sense of integrity. Suffering can occur when any aspect of a person's sense of self is seriously threatened. This can occur when a person's social role, their relationship within a family, or any aspect of their life that provides a sense of integrity or meaning, is threatened. It might occur for instance in a dialysis patient who can no longer work to support his family or a transplant patient who loses her kidney graft and with it a sense of independence, wellness and hope for the future. As Cassell points out, failure to understand the nature of suffering can result in medical intervention that is technically successful but does little to alleviate and can even cause suffering.<sup>10</sup>

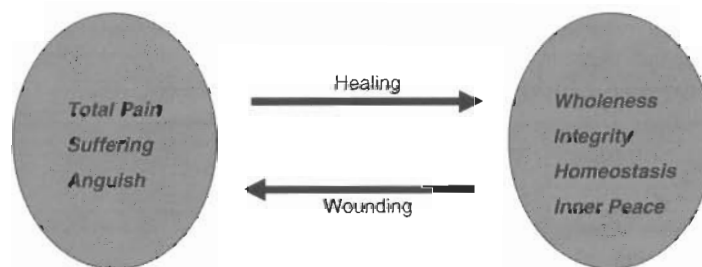
### Evidence that ESRD patients are suffering

Since there is no scale for measuring suffering it is difficult to provide quantitative evidence on the degree of

suffering in ESRD. However, it is impossible to read the qualitative study cited above<sup>7</sup> or the narrative accounts of ESRD patients' lives<sup>2,8</sup> without comprehending that there is extensive suffering. Perhaps the closest to quantitative evidence are the data from studies of 'depression' in ESRD patients. One review study<sup>12</sup> concluded that between one-third and one-half of dialysis patients have at least moderate depression as assessed by a Beck Depression Inventory (BDI) scale of 11 or greater. A more recent study<sup>13</sup> of patients starting dialysis suggested that 44% were 'depressed' as evidenced by a BDI scale of 15 or greater. We are not sure that the answer to these patients' problems is anti-depressive medication but we do believe there is evidence of a significant problem.

### Healing

What can we do to help patients re-establish a sense of integrity and wholeness at a time when their identity is threatened by change, over which they have no control? We believe that the key element is providing a sense of safety. This has little to do with reducing the risk with which modern medicine is so preoccupied. Paradoxically, we need to make it safe to suffer.<sup>14</sup> In his book, *A place of healing* palliative care physician Michael Kearney suggests that providing a safe space where patients can regain a sense of integrity and wholeness in the face of illness and suffering is an ancient part of the health care mandate.<sup>15</sup> Mount and Kearney call this process 'healing',<sup>16</sup> (see Figure 3). Given the right support psycho/social/spiritual transitions can be a time of opportunity as well as spiralling loss. The experience in palliative care shows that some patients can die healed, that is, with a sense of integrity and equanimity despite physical decline.<sup>17</sup> Such healing is also possible for ESRD patients experiencing major transitions in their lives.



Healing is a relational process involving movement towards an experience of integrity and wholeness, which may be facilitated by a caregiver's interventions but is dependent on an innate potential within the patient. It is not dependant on the presence of, or the capacity for, physical well being.

Figure 3 The QOL dialectic.<sup>15</sup>

Take the following dramatic example in a 77-year-old religious woman on haemodialysis treatment:<sup>2</sup>

I was in great stress over a problem ... and nobody seemed to know why but I was going down, down, down in weight and reached a point where I could no longer cry. I had pains across my chest and down my left arm. My bed faced the window. This one night I said 'My God, please tell me whatever is wrong? How can I get rid of myself? I'm afraid of pain. I had a vision of Christ in his white garb with flowing sleeves saying, "Suffer little children to come unto me" ... From that day on I never felt I was alone. I felt I had support with me all the way. That is what has been my stronghold.

Sometimes the process is less dramatic but perhaps equally profound as in the following description from the young man who was quoted above at the time he was beginning dialysis treatment:<sup>2</sup>

I believe now you just do what you have to do to stay alive. You get your priorities straight and little things in life don't matter anymore. Someone once asked me why little things don't bother me. I told them to have a transplant. I always look at the good side of things now because if dialysis had not been invented and transplants had not been done I would have been dead at 19, so the rest is just one big bonus.

### Implications for the care of ESRD patients

If the hypothesis proposed here is true, that psycho/social/spiritual transitions and high mortality cause suffering in ESRD patients, but are also an opportunity for healing, it should have implications for the care that these patients receive. Of course healing cannot be prescribed like a pill and there is a lot more that we need to learn about it. The question is how can we make dialysis and transplant units places that promote a sense of safety and enable healing. The first step is an acknowledgement of the issue and an intention to provide help. Since subjective quality of life (QOL) in ESRD patients does not correlate with clinical parameters such as albumin level, haemoglobin level or KT/V, better technical care does not appear to be the solution. But it appears that what we do for the patient in other ways can make a difference.<sup>18</sup> Since the number of symptoms is associated with subjective QOL in ESRD,<sup>19</sup> we should focus more attention on control of pain and other symptoms. However, as for patients at the end-of-life (EOL), psychosocial and spiritual factors may be as, or more, important.<sup>20</sup> We need to have open,

supportive discussions with patients about the difficulties and high mortality associated with ESRD treatment. Such discussions are well-received by patients in the palliative care context<sup>21</sup> and enhance patients' ability to cope. Since they appear to be well-received when they occur with dialysis patients,<sup>22</sup> the relative infrequency of these discussions in nephrology<sup>23</sup> should be questioned. We should also mobilize appropriate patient-specific additional support at times of major transition. Such support could come from other patients, from nurses, from social workers, from doctors or other healthcare providers. However, training in giving this support, in addition to the technical training that is the foundation of ESRD care, needs to be incorporated into the care of these patients. We need to involve caregivers who devote themselves to understanding the psychological challenges of life with kidney failure and can provide expert counselling and support to these patients. Such persons might also educate and provide support to healthcare workers who interact with patients on a daily basis. We should also consider other forms of expert support such as pastoral counselling, and other modalities that are part of the current palliative care armamentarium.

The best current model for incorporating the above changes in a medical setting is the palliative care team approach<sup>24</sup> and organizations such as the Renal Physicians Association and the American Society of Nephrology,<sup>25,26</sup> have endorsed the need for palliative care for patients with ESRD. Palliative medicine, with its focus on providing a safe, supportive environment for people who are suffering and dying, has a lot of expertise to offer to the care of patients with ESRD. This includes control of pain and other symptoms but also involves attending to the inner life psychological and spiritual needs of patients at a time of major transition (impending death) so that healing can occur. Table 2 gives a list of palliative care interventions that appear relevant to the care of ESRD patients. Multiple modalities are listed because patients differ in their needs and openness to different therapies and this may vary in the same patient depending on their stage in the disease trajectory. Moreover, the care that we

**Table 2**

#### List of palliative care interventions relevant to ESRD patients

Pain and symptom control
Support in constructing a healing environment <sup>34</sup>
Family meetings and support from a social worker <sup>35</sup>
Logotherapy <sup>36</sup> /Existential psychotherapy <sup>37</sup>
Spiritual counseling and support <sup>38</sup>
Support of a bereavement team <sup>39</sup>
Physical, <sup>40</sup> occupational <sup>41</sup> and other related therapies
Guided imagery <sup>42</sup>
Music therapy <sup>43</sup>
Dream work <sup>44</sup>
Art therapy <sup>45</sup>
Pet therapy <sup>46</sup>

are suggesting should not be confined to the EOL and needs to occur throughout the ESRD trajectory whenever major changes or dislocations occur in patients' lives. A recent book on the topic<sup>27</sup> used the term 'supportive care' to carry this connotation. As we learn more about the problem we will probably need to develop new resources targeted specifically at the special needs of ESRD patients. Although we cannot at this stage recommend a single model for the delivery of 'healing care' to ESRD patients we believe that the ethos of palliative medicine as expressed by Cicely Saunders<sup>28</sup> and in the WHO definition of palliative care,<sup>29</sup> is a suitable starting point. The exact form the care takes will depend on the context but, we believe, must also be informed by research involving active patient participation to ensure that the care is tailored to the real needs of patients with renal failure.

### Implications for decision-making

The core question posed at the time patients start dialysis needs to be changed. Instead of asking will dialysis significantly prolong life, the question should be, will the prolongation of life achieved by dialysis be an extension of suffering, or is there a reasonable possibility of healing, and an acceptable QOL? For instance, if it takes six months to adjust to the reality of dialysis, does it make sense to start patients on treatment whose expected survival is three months or less? This is particularly the case if these same patients are likely to experience other major transitions in the course of their short survival (see Table 1). It is not simply a question of whether a given decision is likely to prolong life, but whether it is likely to be associated with effective adaptation to the anticipated life transitions. Of course, such decisions must depend on the individual values of the patient and should be based on in-depth discussions involving the clinical triad (patient, family and health care worker). Patients need to know that they have realistic choices other than pursuing therapy aimed at prolonging life. Too often ESRD patients are left with the impression that active intervention involving dialysis, transplantation, or both is the only credible therapeutic option. One patient<sup>7</sup> stated 'It's either this or the boneyard, one of the two.' A well-developed palliative care option for ESRD patients must become an integral part of all programs treating these patients.

### Implications for Resources

The current level of staffing in most dialysis and transplant units is not sufficient to meet the need for the kind of psycho/social/spiritual care required by

patients on treatment for ESRD. New resources will need to be created to provide the kind of expert humanistic care that these patients require, and to train the staff that now provide technical care to incorporate other aspects of caring in their mandate. This will take a major reorientation of philosophy and resources, analogous to the revolution that palliative care has achieved in the context of oncology.<sup>30</sup> On the other hand, the availability of ESRD palliative/supportive care programs may decrease the need for dialysis places in already overcrowded programs. It is difficult to estimate at this stage either the need for palliative/supportive care resources or the potential for cost savings. However, both are probably substantial. Recent statistics from the USA suggest that currently over 20% of patients stop dialysis,<sup>31</sup> and the number of patients who decide against starting is even higher.<sup>32</sup> We believe that with the availability of good palliative/supportive care, the suffering of these patients could be significantly alleviated, and the number of patients opting not to start or continue dialysis would substantially increase.

### Need for further research

Although there is good reason to believe that patients with ESRD experience adjustment crises at major transition points in the course of their disease,<sup>2,7,8</sup> we need to know a lot more about this phenomenon. At the most basic level we need to know how often patients experience these transitions. Next, we need to know the time course and the characteristics of adaptation for each transition type. It may be that the impact of starting dialysis is different than the impact of a failed vascular access or a failed transplant. There are also likely to be different, and just as profound changes, following positive transitions (e.g., getting a new kidney transplant). We need to know more about the variations in individual response to each major transition. Lastly, we need to find out about the determinants of the response to these transitions. What allows some patients to negotiate difficult transitions with success, while others may never complete them or take a long time to do so? What kinds of intervention and support make a difference? We also need to examine the relationship of mortality to transition periods. The high mortality in widowers in the year after death of a spouse, suggests that major psychosocial transitions can increase the risk of death.<sup>33</sup> The very high mortality in the early months of dialysis treatment could be an example of such a transition-related phenomenon, and there may be others that we have missed, because we have not studied them.



## Conclusions

ESRD is not one health state but many different states with difficult and challenging transitions between them. Patients need help in negotiating these transitions in order to experience an optimal QOL. Expertise relevant to facilitating such transitions comes from a variety of disciplines such as psychology, family therapy, pastoral care and palliative medicine. There is data supporting the concept that transitions between different phases of the disease trajectory are a major problem for patients treated with ESRD,<sup>2,7,8</sup> but more research is needed to delineate the frequency, impact and the determinants of the outcome of such transitions. Points of major transition are also an opportunity for healing. New resources specifically aimed at the psycho/social/spiritual challenges of ESRD patients, are needed to help patients overcome these challenges, achieve the best possible QOL and prevent unnecessary suffering.

## Acknowledgements

I am indebted to Dr Balfour M Mount for encouragement, support and editorial advice; to Dr Eric Cassell for helpful comments and to Mrs Eileen Lavery for help in preparing the manuscript for publication.

## References

- 1 Canadian Organ Replacement Register, Canadian Institute for Health Information. Annual Report 2001, volume 1: dialysis and renal transplantation. Ottawa: The Register; 2001.
- 2 Philips D, (ed.) Heroes: 100 stories of living with kidney failure. Montreal: Grosvenor House Press, 1998.
- 3 Satir V, Banmen J, Gerber J, Gomorri M. The process of change. In *The Satir model: family therapy and beyond*. Palo Alto: Science and Behaviour Books, 1991: 85–119.
- 4 Parkes CM. Bereavement: studies of grief in adult life. London: Penguin, 1998.
- 5 White M. Re-authoring lives: interviews and essays. Adelaide: Dulwich Centre Publications, 1995.
- 6 Campbell J. The hero with a thousand faces. Princeton: Princeton University Press, 1973.
- 7 Gregroy DM, Way CY, Hutchinson TA, Barret BJ, Parfrey PS. Patients' perceptions of their experience with ESRD and haemodialysis treatment. *Qual Health Res* 1998; **8**: 764–83.
- 8 Sollod RN. Beyond a sense of safety: a psychologist's tale of serious chronic illness. *Psychotherapy in Practice*. 2002; **59**: 1397–1409.
- 9 Pyszczynski T, Solomon S, Greenberg J. Terror management research: coping with conscious and unconscious death-related thoughts. In *In the wake of 9/11: the psychology of terror*. Washington: American Psychological Association, 2003: 37–70.
- 10 Cassell EJ. The nature of suffering and the goals of medicine. *N Engl J Med* 1982; **306**: 639–45.
- 11 Cassell EJ. The nature of suffering and the goals of medicine. New York: Oxford University Press, 1991.
- 12 Finkelstein FO, Finkelstein SH. Depression in chronic dialysis patients: assessment and treatment. *Nephrol Dial Transplant* 2000; **15**: 1911–13.
- 13 Watnick S, Kirwin P, Mahnensmith R, Concato J. The prevalence and treatment of depression among patients starting dialysis. *Am J Kid Dis* 2003; **41**: 105–10.
- 14 Stedeford A. Hospice: a safe place to suffer? *Palliat Med* 1987; **1**: 73–74.
- 15 Kearney M. A Place of Healing: working with suffering in living and dying. Oxford: Oxford University Press, 2000.
- 16 Mount BM, Kearney M. Healing and palliative care: charting our way forward. *Palliat Med* 2003; **17**: 657–58.
- 17 Mount BM. Existential suffering and the determinants of healing. *Eur J Palliat Care*. 2003; **10**: 40–42.
- 18 Cohen SR, Boston P, Mount BM, Porterfield P. Changes in quality of life following admission to palliative care units. *Palliat Med* 2001; **15**: 363–71.
- 19 Kimmel PL, Emont SL, Newman JM, et al. ESRD patient quality of life: symptoms, spiritual beliefs, psychosocial factors, and ethnicity. *Am J Kid Dis* 2003; **42**: 713–21.
- 20 Steinhauer KE, Christaakis NA, Clipp EC, McNeilly M, McIntyre L, Tulsky JA. Factors considered important at the end of life by patients, family, physicians and other care providers. *JAMA* 2000; **284**: 2476–82.
- 21 Fallowfield, L. Communication with the patient and family in palliative medicine. In Doyle D, Hanks G, Cherny NI, Calman K, eds *Oxford Textbook of Palliative Medicine*, third edition. Oxford: Oxford University Press, 2004: 101–106.
- 22 Cohen LM, Germain MJ, Poppel DM. Practical considerations in dialysis withdrawal: 'To have that option is a blessing.' *JAMA* 2003; **289**: 2113–19.
- 23 Perry E, Swartz R, Smith-Wheelock L, Westbrook J and Buck C. Why is it difficult for staff to discuss advance directives with chronic dialysis patients? *J Am Soc Nephrol* 1996; **7**: 2160–68.
- 24 Lickiss JN, Turner KS, Pollock ML. The interdisciplinary team. In Doyle D, Hanks G, Cherny NI, Calman K, eds *Oxford Textbook of Palliative Medicine*, third edition. Oxford: Oxford University Press, 2004: 42–45.
- 25 Galla JH and Renal Physicians Association/American Society of Nephrology Working Group. Clinical practice guidelines on shared decision-making in the appropriate initiation of and withdrawal from dialysis. *J Am Soc Nephrol* 2000; **11**: 1340–42.
- 26 Moss AH for the Renal Physicians Association/American Society of Nephrology Working Group. A new clinical practice guideline on initiation and withdrawal of dialysis that makes explicit the role of palliative medicine. *J Pall Med* 2000; **3**: 253–360.
- 27 Chambers EJ, Germain M, Brown E, eds *Supportive care for the renal patient*. Oxford: Oxford University Press, 2004.

- 28 Saunders C. Foreword. In Doyle D, Hanks G, Cherny NI, Calman K, eds *Oxford Textbook of Palliative Medicine*, third edition. Oxford: Oxford University Press, 2004: xxvii-xx.
- 29 World Health Organization. Cancer pain relief and palliative care. 1990: 11-12.
- 30 MacDonald N. Palliative medicine and modern cancer care. In Doyle D, Hanks G, Cherny NI, Calman K, eds *Oxford Textbook of Palliative Medicine*, third edition. Oxford: Oxford University Press, 2004: 24-48.
- 31 US Renal Data System (USRDS). Annual data report: Atlas of end-stage renal disease in the United States. Bethesda, MD: National Institutes of Health, National Institute of Diabetes and Digestive and Kidney Diseases, 2002.
- 32 Mailloux LU. Initiation and withdrawal of dialysis. In Chambers EJ, Germain M, Brown E, eds *Supportive care for the renal patient*. Oxford: Oxford University Press, 2004.
- 33 Helsing KJ, Szklo M. Mortality after bereavement. *Am J Epi* 1981; **114**: 41-52.
- 34 Kearney M. The containment of care. In *A place of healing*. Oxford: Oxford University Press, 2000: 85-90.
- 35 Monroe B. Social work in palliative medicine. In Doyle D, Hanks G, Cherny NI, Calman K, eds *Oxford Textbook of Palliative Medicine*, third edition. Oxford: Oxford University Press, 2004: 1005-1034.
- 36 Frankl V. Man's search for meaning. New York: Simon & Shuster, 1959.
- 37 Yalom ID. Existential psychotherapy. New York: Basic Books, 1980.
- 38 Cassidy JP, Douglas JD. Cultural and spiritual aspects of palliative medicine. In Doyle D, Hanks G, Cherny NI, Calman K, eds *Oxford Textbook of Palliative Medicine*, third edition. Oxford: Oxford University Press, 2004: 949-60.
- 39 Kissane DW. Bereavement. In Doyle D, Hanks G, Cherny NI, Calman K, eds *Oxford Textbook of Palliative Medicine*, third edition. Oxford: Oxford University Press, 2004: 1135-54.
- 40 Doyle L, McClure J, Fisher S. The contribution of physiotherapy to palliative medicine. In Doyle D, Hanks G, Cherny NI, Calman K, eds *Oxford Textbook of Palliative Medicine*, third edition. Oxford: Oxford University Press, 2004: 1050-1056.
- 41 Bray J, Cooper J. The contribution of occupational therapy to palliative medicine. In Doyle D, Hanks G, Cherny NI, Calman K, eds *Oxford Textbook of Palliative Medicine*, third edition. Oxford: Oxford University Press, 2004: 1035-1040.
- 42 Kearney M. Mortally wounded. New York: Scribner, 1996.
- 43 O' Callaghan C. The contribution of music therapy to palliative medicine. In Doyle D, Hanks G, Cherny NI, Calman K, eds *Oxford Textbook of Palliative Medicine*, third edition. Oxford: Oxford University Press, 2004: 1041-1046.
- 44 Kearney M. Dreamwork as earth ascending. In *A Place of Healing: working with suffering in living and dying*. Oxford: Oxford University Press, 2000: 111-141.
- 45 Wood M. The contribution of art therapy to palliative medicine. In Doyle D, Hanks G, Cherny NI, Calman K, eds *Oxford Textbook of Palliative Medicine*, third edition. Oxford: Oxford University Press, 2004: 1063-1067.
- 46 Friedmann, Erika The animal-human bond: health and wellness. In: Fine A, ed. *Animal assisted therapy*. San Diego, CA: Academic Press, 2000: 41-58.