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

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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. 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.

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Narrative

The experience of a teenage boy facing his first dialysis is instructive:

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 c good life.

Transitions in ESRD treatment

Despite his protestations, the young man described above did start dialysis, but one gets some sense of the
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. The interviews were interpreted using grounded theory and three major constructs were identified as: redefinition of self, quality of support; and meanings of illness and treatment. To quote from that paper: ‘The early weeks and months were marked by periods of emotional upheaval and doubting 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 descriptions 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, 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.

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. ESRD patients on treatment have a mortality similar to that of prostate and colon cancer. This creates three challenges:
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 con-
stant threat at a conscious or subconscious level.9

Coping
With the very challenging, inherent risks of ESRD
+reatment 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 1 Time course of changes in QoL in a woman leaving an elusive relationship.6

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’, for Parkes it is ‘gaining a new identity’ and for White it is ‘reincorporation’, and for Campbell it is ‘the return of the hero’. Failure to complete the process leads to continued suffering.

The nature of suffering

Eric Cassell elaborates the nature of suffering in a landmark paper and subsequent book. 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. 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.

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 for the narrative accounts of ESRD patients’ lives 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 concluded that between one-third and one-half of dialysis patients have at least moderate depression as assessed by the Beck Depression Inventory (BDI) scale of 11 or greater. A more recent study 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 answers 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. Paragraphically, we need to make it safe to suffer. 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. Mount and Kearney call this process ‘healing’. (See Figure 3). Given the right support psycho-social/spiritual transitions can be a time of opportunity as well as spiritual 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. Such healing is also possible for ESRD patients experiencing major transitions in their lives.

![Figure 3 The GOL Dialectic](image)
TA Hutchinson

Take the following dramatic example in a 77-year-old religious woman on haemodialysis treatment:

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:

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 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 K/T/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. Since the number of symptoms is associated with subjective QOL in ESRD, 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. 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 and enhance patients' ability to cope. Since they appear to be well received when they occur with dialysis patients, the relative infrequency of these discussions in nephrology 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 and organizations such as the Renal Physicians Association and the American Society of Nephrology 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 (rampending 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

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<th>List of palliative care interventions relevant to ESRD patients</th>
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<td>Pain and symptom control</td>
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<td>Support in constructing a healing environment</td>
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<td>Family meetings and support from a social worker</td>
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<td>Logotherapy and existential psychotherapy</td>
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<td>Spiritual counseling and support</td>
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<td>Support of a bereavement team</td>
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<td>Physical occupational and other related therapies</td>
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are suggesting should not be confined to the EOL and need not occur shortly after the ESRD trajectory when major changes or dislocations occur in patients’ lives. A recent book on the topic used the term ‘supportive care’ to convey this notion. 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 of the delivery of ‘supportive care’ to ESRD patients we believe that the ethos of palliative medicine as expressed by Cicely Saunders is an appropriate 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 team (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 stated, ‘it’s either this or the honeycomb, 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 psychosocial/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 practice. This will take a high level of philosophical commitment, analogous to the revolution that palliative care has achieved in the context of oncology. On the other hand, the availability of ESRD palliative/supportive care programs may increase 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 and the number of patients who decide against starting is even higher. 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, 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 transplant. There are 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. 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, 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 psychological/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 Ballou 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.

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