The Development of the Life Evaluation Questionnaire for Hemodialysis Patients

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Abstract

Objective: Existing quality of life measures fail to incorporate patients’ own understanding of evaluation of life following the diagnosis of end stage renal failure (ESRF). Previous qualitative research has identified ways of evaluating life that have not been captured by existing quantitative research and that can be possible targets for clinical practice. Nonetheless, quantification is necessary if clinicians are to be informed of potentially important ways of evaluating life. It is also necessary to devise patient-derived measures of quality of life if the aim is also to monitor improvement in ways of evaluating life following interventions devised to change them.

Method: Three studies were carried out. In the first two, the ways of evaluating life that were previously identified were quantified, a questionnaire that measures ways of evaluating life was developed, and the clinical utility of this questionnaire was examined in a sample of 156 hemodialysis patients. In the third study the predictive validity of this questionnaire was examined in a sample of 153 hemodialysis patients.

Results: The findings identified a number of targets for clinical practice. These included feeling unable to ‘get round’ limitations, mixed negative feelings about caregivers, and failure to find something positive about ESRF. The newly developed 3 subscales of life evaluation were internally consistent. The findings also show that these subscales had construct and predictive validity.

Conclusion: The present studies provide a disease-specific life evaluation questionnaire consisting of 3 subscales for use in hemodialysis patients that can supplement existing generic quality of life measures.

Keywords: ESRF, Hemodialysis, quality of life, adjustment.

INTRODUCTION

In end stage renal failure (ESRF) the assessment of adjustment and quality of life has involved the use of generic adjustment and quality of life measures. Some of these measures assess these areas through a number of domains chosen a priori; that is, they reflect professional views of adjustment. On the other hand, alternative measures, such as the Hemodialysis Quality of Life Questionnaire (HQLQ) (Churchill et al., 1991) and the Renal-Dependent Individualized Quality of Life Questionnaire (RDQOL) (Bradley, 1997) assess these areas on the basis of in-depth interviews with patients (see also Krespi et al., 2008).

Nevertheless, they have fallen short in two main ways (Krespi et al., 2008). First, our previous research findings indicated that patients experienced positive changes in their character (Krespi et al., 2008), suggesting that adjustment to ESRF could involve the attachment of positive ‘meaning’ to the disease (Shontz, 1975) or some form of existential growth (Sodergren et al., 2004), as in other chronic diseases (Salmon et al., 1996; Sodergen and Hyland, 2000) (see also Krespi et al., 2008).

Second, our previous research findings identified a wide spectrum of both positive and negative aspects of hemodialysis patients’ experience of their caregivers. More specifically, patients perceived their caregivers as...
lacking support and understanding, and as sources of difficulty and distress in that patients experienced resentment, anger, disappointment, and guilt in their relationships with them. Patients also perceived that their feelings of dependence were imposed by their caregivers, rather than by the illness itself. This suggests that social aspects of ESRF are more complex than previous research indicates. More specifically, this evidence indicates that the social aspects of adjustment to ESRF involve its interference with social activities and roles, and the availability of perceived social support (see also Krespi et al. 2008).

Our previous findings are useful in highlighting not only the shortfalls of existing quality of life measures, but also possible targets for clinical practice. Nonetheless, to inform their clinical practice clinicians require evidence, not just the range of patients’ ways of evaluating life, but their frequency. Therefore, it is necessary to quantify these findings. Although quantification of patients’ accounts will help to identify potentially important ways of evaluating life, it is not certain that these will influence adjustment. It is also premature for researchers to devise interventions to target them before it is shown that they influence adjustment. Moreover, it will be difficult to monitor improvements in ways of evaluating life should interventions be devised to change them. For this reason, it is also necessary to devise questionnaires that reliably and validly measure them, and to examine the clinical utility of these questionnaires.

In line with this reasoning the present study was designed with 3 main aims. The first was to quantify the range of ways of evaluating life that were identified in our previous study (Krespi et al., 2008) and to develop a questionnaire that measure ways of evaluating life (study 1a). The second was to examine the clinical utility of this questionnaire in explaining variability in adjustment (study 1b). The third was to examine the predictive validity of the questionnaire (study 2).

**Study 1a**

This study aimed to quantify the ways of evaluating life identified in our previous study (Krespi et al., 2008).

**METHOD**

**Sample**

Consecutive attenders (n = 166) at the hemodialysis ward and 1 satellite unit of a university hospital were asked to participate. The final sample consisted of 156 patients (87 male [56%] and 69 female [44%]). Mean age was 54 years (range: 17-81 years) and mean duration of hemodialysis was 3 years (range: 1 month-20 years). Sixty-seven patients (43%) received hemodialysis at the hospital and 89 (57%) at satellite units. Fifteen patients (10%) were employed, 44 (28%) were unemployed, 72 (46%) were retired, and 25 (16%) were homemakers. Exclusion criteria included the inability to speak or understand English and the presence of a medical condition preventing participation, including dementia related to hemodialysis treatment and blindness.

**Procedure**

On the Life Evaluation Questionnaire for Hemodialysis Patients, each of the 35 items represents a type of evaluation of life that we identified previously (Krespi et al., 2008). We kept items as far as possible to patients’ own words. In a pilot study with 10 patients the comprehensibility and comprehensiveness of the questionnaire was checked. No item was added to the questionnaire during this process.

**Statistical Analyses**

Frequencies and percentages were calculated for each item. The questionnaire asked patients to rate individual items on a 5-point scale. For unipolar items, patients indicated the degree of agreement/disagreement with each item on a 5-point scale, ranging from 1 (completely agree) to 5 (completely disagree), and 3 representing uncertainty. For bipolar items, the patients indicated the degree of agreement with each item on a 5-point scale, ranging from 1 (completely agree with the left pole of an item) to 5 (completely agree with the right pole of an item), and 3 representing uncertainty. Those responding at the midpoint were disregarded. The structure of the questionnaire was assessed by principal components analysis. The number of components to retain was determined with the help of a scree test before varimax rotation. Items loading at > 0.40 were used to interpret the components. Component-based scale scores were calculated by summing scores on the items that loaded on each component. In reporting bipolar items, the sign of the loading indicated which pole to associate with the component. Reliability of the scales was established by Cronbach's alpha coefficients; coefficients of 0.87 and 0.74 were considered good, and 0.67 was considered acceptable.

**RESULTS**

ESRF and its treatment were perceived as imposing limitations by approximately 50% of the patients (item 30) (Table 1). Nevertheless, these constraints were gen-
erally viewed as problems that could be circumvented (item 4). Most agreement concerned items expressing satisfaction with caregivers. Caregivers were often described as supportive and caring; however, many patients recounted negative experiences of their caregivers. These included lack of support and understanding (items 1 and 2). Patients also frequently experienced their caregivers as sources of distress and difficulty. Nevertheless, the number of patients who reported being helped (item 1) was higher than the number of patients who felt worried or guilty about them (items 9, 10, and 13). The number of patients who were dissatisfied with their caregivers due to over-protection (item 3) was equal to the number of patients who were dissatisfied due to lack of support (item 1). A small but significant number of patients perceived resentment, anger, and disappointment with their caregivers (items 31 and 33) (Table I).

Approximately 50% of the patients reported one of several diverse emotional difficulties (items 17-20) and a significant minority felt suicidal (item 34). Moreover, a smaller number felt angry or alienated from those around them (items 5, 14, and 27). Worsening of fundamental aspects of character or personality was also reported by many; about 20% of the patients felt that they had become ‘more selfish’ (item 29) and about 33% reported that they had become ‘harder’ towards life (item 21). Most patients, however, perceived some positive effects of their illness on their character and on their lives, including becoming more considerate, having a better understanding of other people, and feeling closer to people (items 15, 16, and 25), although many perceived nothing positive in their illness (Table I).

Three components explained nearly one-third (32.3%) of the variance in the items. Negative reflection had an eigen value of 7.19 and explained 19.40% of the variance. This had both an emotional component and a cognitive component. The emotional component included feeling irritable, fed up, and feeling sorry for oneself, whereas the cognitive component included preoccupation, disillusion, and worry about death. Component 2 had an eigen value of 2.65 and explained 7.20% of the variance. This described ways in which patients ‘got on with Life’ despite the difficulties that they experienced because of their illness and its treatment. Component 3 had an eigen value of 2.11 and explained 5.70% of the variance. This described alienation; more specifically disappointment, selfishness, isolation, and bitterness in social relationships. As a result of these analyses, 29 of the 35 items were retained. Cronbach’s alpha coefficients were also satisfactory for these 3 scales (Table I).

**Study 1b**

**Introduction**

This study examined the clinical utility of the Life Evaluation Questionnaire for Hemodialysis Patients in explaining variability in adjustment.

The relationship of the subscales of the present questionnaire to adjustment can be understood in terms of the construct of ‘assimilation of the illness.’ This refers to a kind of adjustment in which people mature emotionally as a result of their illness, rather than overcome it (Salmon, 2000). Specifically, some items included in ‘getting on with Life’ suggest that it may represent patients’ attempts to assimilate their illness into their lives. It describes the ways in which patients change their attitude towards life as a result of the demands of ESRF. It is envisaged that this process is likely to facilitate attempts to make life more meaningful. This, in turn, is likely to be associated with greater satisfaction with life despite ESRF and its demanding treatment. On the other hand, negative reflection and alienation represent patients’ emotional difficulties as a result of having an incurable illness and having to follow a demanding treatment regimen. Some evidence (Felton and Revenson, 1984) indicates that perception of a chronic illness, other than ESRF, as an opportunity for personal growth is associated with better life satisfaction. Therefore, these subscales should be associated with quality of life and emotional adjustment.

In order to examine these relationships, the following hypotheses were formulated:

1) Getting on with Life will be associated with better quality of life and emotional adjustment.

2) Negative Reflection and Alienation will be associated with poorer quality of life and emotional adjustment.

**METHOD**

**Sample**

The sample and the exclusion criteria of this study were same as those for Study 1a.

**Procedure**

In order to test the hypotheses emotional adjustment and quality of life were measured. Emotional adjustment was measured by the Hospital Anxiety and Depression Scale (Zigmond and Snaith, 1983), which consists of
7 items that measure the severity of depression and 7 items that measure the severity of anxiety. For each item, patients are asked to choose 1 of 4 alternatives to indicate how they feel. This yields separate scores for anxiety and depression. It is a widely used measure of emotional adjustment in patients with a physical illness. It has ad-

### Table I. Frequencies and percentages of each item on the Life Evaluation Questionnaire for Hemodialysis Patients and the construct validity of this questionnaire.

<table>
<thead>
<tr>
<th>Item</th>
<th>Frequencies</th>
<th>%</th>
<th>Negative Reflection</th>
<th>Getting on with Life</th>
<th>Alienation</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. People close to me help me to do things I can’t do (disagree)</td>
<td>130/15</td>
<td>83/10</td>
<td>0.48</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. People close to me understand how my illness affects me (disagree)</td>
<td>20/129</td>
<td>13/83</td>
<td>0.58</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. People who look after me let me do things for myself</td>
<td>124/15</td>
<td>80/10</td>
<td>0.56</td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. If I make special arrangements I can get round the limitations which my illness and treatment cause me</td>
<td>115/19</td>
<td>74/12</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. It does not upset me to see people doing things that I can’t do</td>
<td>100/36</td>
<td>64/23</td>
<td>0.46</td>
<td></td>
<td></td>
</tr>
<tr>
<td>6. I always think about how my illness and its treatment limit what I can do (disagree)</td>
<td>100/27</td>
<td>64/17</td>
<td>0.49</td>
<td></td>
<td></td>
</tr>
<tr>
<td>7. I will have a transplant at some point</td>
<td>95/33</td>
<td>61/21</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>8. People are affectionate to me (disagree).</td>
<td>98/30</td>
<td>63/19</td>
<td>0.68</td>
<td></td>
<td></td>
</tr>
<tr>
<td>9. People close to me are under pressure because of my illness (disagree)</td>
<td>96/44</td>
<td>62/28</td>
<td>0.45</td>
<td></td>
<td></td>
</tr>
<tr>
<td>10. I feel sorry for people close to me (disagree)</td>
<td>90/47</td>
<td>58/30</td>
<td>0.42</td>
<td></td>
<td></td>
</tr>
<tr>
<td>11. I am confident</td>
<td>88/40</td>
<td>56/26</td>
<td>0.41</td>
<td></td>
<td></td>
</tr>
<tr>
<td>12. I can concentrate</td>
<td>86/46</td>
<td>55/30</td>
<td>0.48</td>
<td></td>
<td></td>
</tr>
<tr>
<td>13. I feel guilty about people who look after me</td>
<td>83/56</td>
<td>53/36</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>14. My temper is no worse than before</td>
<td>82/54</td>
<td>53/35</td>
<td>0.48</td>
<td></td>
<td></td>
</tr>
<tr>
<td>15. I am more considerate of other people than I was before</td>
<td>81/36</td>
<td>52/23</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>16. I understand other people better than I did before</td>
<td>81/39</td>
<td>52/25</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>17. I feel fed up</td>
<td>68/63</td>
<td>44/40</td>
<td>0.79</td>
<td></td>
<td></td>
</tr>
<tr>
<td>18. I feel irritable</td>
<td>64/56</td>
<td>41/42</td>
<td>0.83</td>
<td></td>
<td></td>
</tr>
<tr>
<td>19. I am bored</td>
<td>62/77</td>
<td>40/49</td>
<td>0.71</td>
<td></td>
<td></td>
</tr>
<tr>
<td>20. I get worked up</td>
<td>60/75</td>
<td>39/48</td>
<td>0.75</td>
<td></td>
<td></td>
</tr>
<tr>
<td>21. I have become “harder” towards life</td>
<td>54/85</td>
<td>35/55</td>
<td>0.56</td>
<td></td>
<td></td>
</tr>
<tr>
<td>22. Physically, I am better off than most people</td>
<td>53/76</td>
<td>34/49</td>
<td>0.42</td>
<td></td>
<td></td>
</tr>
<tr>
<td>23. I am frightened of the future</td>
<td>51/79</td>
<td>33/51</td>
<td>0.41</td>
<td></td>
<td></td>
</tr>
<tr>
<td>24. I can do my daily chores</td>
<td>49/77</td>
<td>31/49</td>
<td>0.47</td>
<td></td>
<td></td>
</tr>
<tr>
<td>25. I am no closer to people than I was before</td>
<td>43/67</td>
<td>28/43</td>
<td>0.44</td>
<td></td>
<td></td>
</tr>
<tr>
<td>26. I worry about death</td>
<td>41/97</td>
<td>26/62</td>
<td>0.43</td>
<td></td>
<td></td>
</tr>
<tr>
<td>27. I feel angry</td>
<td>41/94</td>
<td>26/60</td>
<td>0.73</td>
<td></td>
<td></td>
</tr>
<tr>
<td>28. I could do more in my life</td>
<td>36/97</td>
<td>23/62</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>29. I am more selfish than I was before</td>
<td>33/102</td>
<td>21/65</td>
<td>0.45</td>
<td></td>
<td></td>
</tr>
<tr>
<td>30. I can still do the things I want to do</td>
<td>32/74</td>
<td>21/47</td>
<td>0.55</td>
<td></td>
<td></td>
</tr>
<tr>
<td>31. I feel bitter at people close to me</td>
<td>29/117</td>
<td>19/75</td>
<td>0.63</td>
<td></td>
<td></td>
</tr>
<tr>
<td>32. I feel sorry for myself</td>
<td>29/103</td>
<td>19/66</td>
<td>0.61</td>
<td></td>
<td></td>
</tr>
<tr>
<td>33. My illness has made me disappointed in people</td>
<td>25/113</td>
<td>16/73</td>
<td>0.56</td>
<td></td>
<td></td>
</tr>
<tr>
<td>34. I feel like doing away with myself</td>
<td>15/128</td>
<td>10/82</td>
<td>0.52</td>
<td></td>
<td></td>
</tr>
<tr>
<td>35. My illness has made my home life better</td>
<td>12/104</td>
<td>8/67</td>
<td>0.48</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cronbach’s Alpha</td>
<td></td>
<td></td>
<td>0.87</td>
<td>0.74</td>
<td>0.67</td>
</tr>
</tbody>
</table>
equate internal consistency and construct validity (Zigmond and Snaith, 1983).

Quality of life was measured with the Ladder Scale (Andrews and Withey, 1976) and 2 summary scales of the Medical Outcomes Studies-Short Form Health Survey Questionnaire (SF-36) (Ware and Sherbourne, 1992; Ware et al., 1994). The Ladder Scale consists of a ladder with 9 rungs. Patients are asked to choose one of the rungs to show where on the ladder their life is, ranging from 9 (best life I could expect to have) to 1 (worst life I could expect to have). This scale also has adequate test-retest reliability (Andrews and Withey, 1976) and construct validity (Atkinson, 1982).

The SF-36 is a generic measure of multi-dimensional health status, which is widely used in both the general population and in patients with a chronic physical illness, including ESRF (Hays et al., 1994; Horne and Weinman, 1995). It consists of 36 items (Ware and Sherbourne, 1992) that measure 8 dimensions of life: Physical functioning, social functioning, role limitations and physical problems, role limitations and emotional problems, mental health, vitality, pain, and general health perception. For each item, patients are asked to choose one of the alternative answers provided. Separate scores can be calculated for each dimension, ranging from 0 to 100 (Ware et al., 1993) and 2 summary scales can be generated (Ware et al., 1994), including the Physical Health Summary Scale and the Mental Health Summary Scale. Both the measure itself and its summary scales have adequate psychometric properties, including internal consistency, test-retest reliability, and construct validity (Brazier et al., 1992; Ware et al., 1994). The summary scales have been effectively used with hemodialysis patients (DeOreo, 1997).

Therefore, the assessment protocol included these measures and the Life Evaluation Questionnaire for Hemodialysis Patients. Patients were asked to take part in the study while they were on hemodialysis, but 50% of the patients completed the assessment protocol at home.

**RESULTS**

Hypothesis 1 examined whether patients who reported getting on with life would report better quality of life and adjustment. The findings support this hypothesis. Getting on with life was associated with better emotional adjustment ($r = -0.50, P \leq 0.001$ and $r = -0.61, P \leq 0.001$, respectively, for anxiety and depression) and quality of life ($r = 0.36, P \leq 0.001$, $r = 0.37, P \leq 0.001$, and $r = 0.55, P \leq 0.001$, respectively, according to the Ladder Scale, SF-36 Physical Health Summary Scale, and SF-36 Mental Health Summary Scale).

Hypothesis 2 examined whether patients who reported engaging in negative reflection and feeling alienated would report poorer quality of life and emotional adjustment. The findings provide partial support for this hypothesis. Negative reflection was associated with poorer emotional adjustment ($r = 0.67, P \leq 0.001$ and $r = 0.54, P \leq 0.001$, respectively, for anxiety and depression) and quality of life ($r = -0.60, P \leq 0.001$, $r = -0.24, P < 0.01$, and $r = -0.65, P \leq 0.001$, respectively, for the Ladder, SF-36 Physical Health Summary Scale, and SF-36 Mental Health Summary Scale). Alienation was associated with more depression ($r = 0.27, P \leq 0.001$), but not with anxiety ($r = 0.16$) or quality of life ($r = -0.11, r = -0.07$, and $r = -0.14$, respectively, for the Ladder, SF-36 Physical Health Summary Scale, and SF-36 Mental Health Summary Scale).

**Study 2**

**Introduction**

This study examined the predictive validity of the Life Evaluation Questionnaire for Hemodialysis Patients. This study also examined the effects of relaxation and visual imagery techniques on adjustment and quality of life, but those findings are not reported here (Krespi et al. 2008 accepted)

A specific visual imagery technique constituted the intervention. The control procedures included an active control and a no-treatment control. The former consisted of relaxation training and general imagery techniques. Relaxation training consisted of progressive muscle relaxation by suggestions of warmth, comfort, and relaxation. General visual imagery included special place imagery, descent imagery, and counting that aimed at deepening the relaxation state. Special place imagery consisted of suggestions to help build a mental picture of a pleasant, safe, and relaxing place (such as a garden or a beach), and was based...
Figure 1. An outline of the predictive validity of the Life Evaluation Questionnaire for Hemodialysis Patients. Values are path coefficients. Arrows indicate hypothesized causal relationships (single-headed) and covariances (double-headed). \(*p < 0.05.\)
on the utility of metaphors in therapy. The metaphor that the patients were provided with was a ‘filter’. During the specific imagery, patients were encouraged to build a mental image of the hemodialysis machine and were given suggestions to reframe hemodialysis as a positive and a valuable experience. The suggestions incorporated the images of hemodialysis that we identified previously (Krespi et al., 2004). The interventions were delivered via audiotape. Patients listened to the tape while on hemodialysis 3-4 times per week for a period of 6 weeks.

To examine the predictive validity of the present questionnaire the hypotheses tested in Study 1b were revisited and were amended to examine whether the present subscales at pre-treatment were able to predict emotional adjustment and quality of life post-treatment and at follow-up. The hypotheses were:

1) Negative Reflection and Alienation pre-treatment and post treatment will predict more depression and poorer quality of life post-treatment and at follow-up, respectively.
2) Getting on with Life pre-treatment and post-treatment will predict less depression and better quality of life post-treatment and at follow-up, respectively.

**Method**

**Sample**

The sample included consecutive attenders (n = 203) at the hemodialysis ward of a university hospital and its 4 satellite units. In all, 153 patients agreed to participate, (106 [69%] male and 47 [31%] female). Mean age was 54 years (range: 23-85 years); 28 patients (18%) had been on hemodialysis for 1-6 months, 26 (17%) for 7 months-1 year, 55 (36%) for 1-3 years, 35 (23%) for 3-8 years, and 9 (6%) for more than 8 years. In all, 55 patients (36%) received hemodialysis at the hospital and 98 (64%) at satellite units. Eighteen patients (12%) were employed, 49 (32%) were unemployed, 69 (45%) were retired, and 17 (11%) were housewives/homemakers. The exclusion criteria of this study were same as those for studies 1a and 1b.

Patients who agreed to participate were randomly assigned to 3 groups. During the course of the study, 23 patients withdrew at different stages. In addition, 10 patients died, 1 was transplanted, and 1 changed treatment modality. To examine whether the final sample was biased by withdrawal, the 3 groups of patients were compared on demographic and medical variables: Patients who completed the study together with those who died or changed treatment modality (n = 130), patients who withdrew (n = 23), and patients who refused to take part at the outset (n = 50). These 3 groups were not different from each other (Table II).

**Procedure**

Patients were approached while they were on hemodialysis. Nearly 90% of the patients completed the assessment protocol at home. In order to test the hypotheses and to minimize the risk of a type-1 error, indices of emotional adjustment and quality of life were limited to two. As depression is one of the main emotional difficulties observed in hemodialysis patients, it was chosen as the index of emotional adjustment. This was measured by the Hospital Anxiety and Depression Scale (Zigmond and Snaith, 1983). For an index of quality of life, the Ladder Scale (Andrews and Withey, 1976) was chosen because it is a global measure of life evaluation. Please refer to study 1b for more details about these measures. Patients were asked to complete the assessment protocol on 3 occasions: At the start of the study, in the post-treatment stage (weeks 9-10), and at the 3-month follow-up (weeks 21-22).

**Statistical Analyses**

Path analyses were used to examine the predictive validity of the sub-scales of the life evaluation questionnaires. These are essentially a way of computing multiple regression analyses simultaneously. The criterion for significance was P < 0.05. Analyses were performed using EQS v.5.7b.

**Results**

The results of the path analyses are given in Figure 1. Path coefficients are beta coefficients. Significant coefficients indicate significant paths after controlling for additional influences on the predictor variable.

Negative Reflection and more Alienation predicted poorer quality of life post-treatment. These pertain to the significant path coefficients of –0.33 in Figure 1a and –0.24 in Figure 1c. More Negative Reflection and more Alienation post-treatment predicted poorer quality of life at follow-up. These pertain to the significant path coefficients of –0.41 in Figure 1a and –0.20 in Figure 1c. For depression, the direction of the influence was opposite to that hypothesized. That is, depression pre-treatment predicted negative reflection (path coefficient of 0.26 in Figure 1b) and alienation post-treatment (path coefficient of 0.25 in Figure 1d), and depression post-treatment predicted negative reflection (path coefficient of 0.21 in Figure 1b) and alienation at follow-up (path coefficient of 0.21 in Figure 1d). These findings, therefore, provide partial support for the first hypothesis.

Getting on with Life pre-treatment predicted better quality of life post-treatment (path coefficient of 0.22 in Figure 1e) and Getting on with Life post-treatment predicted better quality of life at follow-up (path coefficient of 0.26 in Figure 1e). As in Negative Reflection and alienation, for depression, the direction of the influence was opposite to that hypothesized. More specifically, depression pre-treatment predicted Getting on with Life post-treatment (path coefficient of –0.43 in Figure 1f) and depression post-treatment predicted Getting on with Life at follow-up (path coefficient of –0.19 in Figure 1f). These findings provide partial support for the second hypothesis.

**General Discussion**

Quantification of the ways of evaluating life in study 1a helped us to identify targets for clinical practice. A
significant minority of patients felt unable to get round the limitations caused by ESRF and its treatment. Clinicians might use our qualitative findings concerning different ways of getting round these limitations (Krespi et al., 2008) in developing interventions to promote better adjustment and to provide help to this group at risk of adjustment difficulties.

Satisfaction with caregivers was common, but again, a significant minority reported their caregivers lacked understanding, experienced guilt, resentment, disappointment, and dependency in their relationships with them, in addition to feeling alienated from other people. The importance of social support in facilitating adjustment to ESRF has been previously reported (Kimmel et al., 1995; Elal and Krespi, 1999). Based on this finding, it is likely that those patients who experience these difficulties with caregivers and other people will also be at risk of adjustment difficulties. As such, these difficulties should be targets of clinical practice and consultation. Again, our previous qualitative findings concerning the mixed feelings about caregivers (Krespi et al., 2008) may guide clinicians in devising interventions. These interventions should specifically aim at better communication with caregivers and, in turn, better adjustment to ESRF.

Consistent with previous reports of anxiety and depression (Cukor et al., 2007), many patients experienced emotional deterioration. Nevertheless, interestingly, most perceived some positive effect of their illness on their character and life. This indicates that adjustment to ESRF involves the attachment of positive meaning to the disease, and that emotional deterioration and perception of positive effects of illness can coexist. McGee and Bradley (1994) reported the importance of meaning in ESRF, but the present findings showed ways in which meaning is attached to ESRF. It is likely that the perception of improvements of this kind will be a mechanism whereby adjustment is preserved or facilitated in ESRF. Unfortunately, a small but significant number of patients perceived nothing positive attributable to ESRF. The absence of anything positive attributed to ESRF should, therefore, be another target of clinical practice or consultation; that is, patients who cannot perceive anything positive in their illness will need particular help adjusting by finding some positive meaning in their illness, and our previous qualitative findings (Krespi et al., 2008) might help to guide clinicians in developing interventions to facilitate the attachment of some positive meaning to ESRF.

During the principal component analyses a small number of items were not retained. It is difficult to know exactly why these items were not retained. It may be that some items reflected internalization of professionals’ views on how to adjust to ESRF and its treatment, and these may not have been important aspects of patients’ own evaluation of life. These may include items concerned with making special arrangements to get round the limitations, having a transplant, or feeling that one can do more in life. It is often customary to advise ESRF patients to do so in routine medical consultations and to initiate plans or procedures to facilitate these processes, such as undergoing dialysis while on vacation.

The findings also indicate that the subscales of the Life Evaluation Questionnaire for Hemodialysis Patients were internally consistent. Moreover, the findings also suggest that the present subscales are evaluative; that is, they do not measure life evaluation merely in terms of disruption or interference caused by ESRF and its treatment; instead, the items on the present subscales allowed patients to actively evaluate their lives in that they measure patients’ opinion and attitudes about their lives with ESRF. The patients evaluated their lives not as victims on the contrary as self-regulatory individuals that shaped their own adjustment by forming opinions about them. Each subscale incorporated items that were related to different aspects of life evaluation, including emotional reactions and psychosocial function. Negative Reflection included fears about the future, and evaluations of changes in character, as well as boredom, anger, and gloom. Similarly, alienation was not simply the perception that others fail to provide emotional support, but also included the perception of changes in one’s own nature that contributed to isolation from others. Getting on with life included confidence in one’s ability as well as the perception that others were not burdened by the patient’s illness.

Two hypotheses were tested in study 1a in order to examine the clinical utility of the Life Evaluation Questionnaire for Hemodialysis Patients. The first hypothesis was that patients who reported negative reflection and alienation would report poorer emotional adjustment and quality of life. The second hypothesis was that those who reported getting on with life would report better emotional adjustment and quality of life. The findings provide partial support for these hypotheses. Alienation was associated with more depression, but not with quality of life or anxiety, whereas negative reflection was associated with more depression and anxiety, and poorer quality of life. Similarly, getting on with life was also associated with less depression and anxiety, and better quality of life. This suggests that the present scales relate to
measures of quality of life and emotional adjustment in predictable ways. Nevertheless, the modest associations and the evaluative nature of the present scales suggest that they measured something other than quality of life and emotional adjustment as they are usually conceptualized, and that they are different from both existing conventional quality of life scales that measure negative changes and interference, and quality of life measures developed on the basis of patients’ views, such as the Renal-Dependent Individualized Quality of Life Questionnaire (RDQOL) (Bradley, 1997). Therefore, the present scales were not recognizable as conventional quality of life and adjustment scales, and therefore, they provided useful disease-specific measures of life evaluation.

Study 2 examined the predictive validity of the Life Evaluation Questionnaire for Hemodialysis Patients. The first hypothesis was that patients who reported negative reflection or felt alienated, pre-treatment and post-treatment, would report more depression and poorer quality of life post-treatment and at follow-up, respectively. The findings provide partial support for this hypothesis. Negative Reflection and Alienation pre-treatment and post treatment each subsequently predicted poorer quality of life. This suggests that being upset or alienated early in treatment may be a risk factor for poor quality of life later on. Contrary to the hypothesized direction of cause and effect, depression pre-treatment predicted negative reflection and alienation, both post-treatment and at follow-up. This finding suggests that if patients are depressed early in treatment, they will become upset and alienated later on. Further research is required to examine these relationships.

The second hypothesis was that patients who reported more getting on with life, pre-treatment and post-treatment, would report less depression and better quality of life post-treatment and at follow-up, respectively. This hypothesis was also partially supported. Getting on with life, pre-treatment and post-treatment, subsequently predicted better quality of life. This suggests that perhaps getting on with life early in treatment promotes better quality of life later on. This also remains to be tested. Again, contrary to the hypothesized direction, depression pre-treatment predicted less Getting on with Life, both post-treatment and at follow-up. This finding suggests that perhaps if patients are depressed early in treatment they will also be less able to get on with lives later on. Further research is also required to examine these relationships.

In general, the findings provide some support for the clinical utility, construct validity, and predictive validity of the present subscales. Moreover, the present subscales also have content validity because of the way that they were designed. The findings also indicate the great importance of depression for patients’ overall adjustment.

The present findings might guide future research in a number of ways. First, clinicians and researchers can use the present subscales as disease-specific ways of evaluating life. Second, the present subscales can be used to monitor patients’ adjustment or to assess their needs in a way that is sensitive to their perspectives (editorial, 1995), and can evaluate the effects of interventions. Third, they can supplement conventional quality of life measures. Fourth, the present findings help to identify targets for psychological or educational interventions that can improve emotional adjustment and quality of life.

Nonetheless, it is not clear how the present subscales converge or diverge from existing quality of life and adjustment measures. In particular, it would be useful if future research examines the ways in which the present subscales converge or diverge from the Renal-Dependent Individualized Quality of Life Questionnaire (RDQOL) (Bradley, 1997). This would be useful because the latter scale was not only developed on the basis of patients’ views, but it also adopted an ideographic approach to the measurement of quality of life.

It is also not known how the present subscales will be relevant to other cultural groups. There was a qualitative phase in the development of the Life Evaluation Questionnaire for Hemodialysis Patients that we previously published (Krespi et al., 2008). This previous study and the present study were both conducted with English-hemodialysis patients. The ways of evaluating life that were identified and then helped to form the questionnaire will likely reflect cultural and societal factors. The importance of culture and social factors in adjusting to chronic physical illness has been reported previously (Radley 1989, Radley 1994). It is likely that factors such as societal beliefs towards illness, adversity, disability and limitations, societal barriers to adjustment and recovery, the value attached to close relationships in a culture and to independence versus dependence issues, and societal views about emotional expression will arguably be reflected in patients’ evaluations of their lives following the diagnosis of ESRF. Yet, it is difficult to know the exact nature of these reflections; therefore, before its use in other cultures, future research should also examine the reliability and validity of the present subscales in these cultures.
REFERENCES


Krespi MR, Oakley D, Bone M et al. (accepted) The effects of visual imagery on adjustment and quality of life of hemodialysis patients. Turkish J Psychiatry.


