

Hemodialysis Patients' Evaluation of Their Lives

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Abstract

Objective: The experience of end-stage renal failure (ESRF) should not be understood merely in terms of functional impairment and increases in emotional distress. It should be assessed in its own right. Qualitative research is necessary for describing patients' own experience of ESRF so that findings are not influenced by psychological theory.

Method: The typical sampling method was used to select the sample, which consisted of 16 hemodialysis patients. Thematic analysis of patient interviews followed established conventions so as to ground the analysis in the data, rather than pre-existing ideas.

Results: Qualitative analysis identified different ways in which the patients evaluated their lives. The patients described the effects of ESRF on their lives primarily in terms of attitudes towards limitations, mixed feelings about caregivers, and changes in their own character. Caregivers were frequently described as supportive, but patients also perceived them as sources of distress and difficulty. ESRF and its treatment were reported to have worsened not only the patients' emotional states, but also aspects of their character; however, the effect of ESRF also involved the experience of positive changes in character.

Conclusion: The present study provides a detailed systematic account of how hemodialysis patients evaluated their lives. Some of the findings provide details about how the psychological processes that have been previously reported operate in practice, which clinicians and researchers need to understand; however, some findings cannot readily be explained according to existing ideas. The findings, therefore, identify potential targets for educational intervention to improve patient adjustment.

Key Words: ESRF, Hemodialysis, quality of life, adjustment

INTRODUCTION

The experience of end stage renal failure (ESRF) and hemodialysis is not a simple function of physical condition. It should be assessed in its own right. In an attempt to understand patients' experience of the effects of ESRF on life, the literature has focused on the concept of adjustment. In ESRF, adjustment has been typically assessed by generic quality of life measures. Some of these measures include a number of domains chosen a priori that reflect professional views of what is important in adjustment. Alternative measures have been designed on the

basis of in-depth interviews with patients, including the Hemodialysis Quality of Life Questionnaire (Churchill et al., 1991) and Renal-Dependent Individualized Quality of Life Questionnaire (Bradley, 1997).

However, because they are guided by professional views or theoretical assumptions on adjustment, these measures do not incorporate 2 important views or findings. First, adjustment to a physical illness can involve attachment of personal meaning to the illness (Shontz, 1975), even to the extent of perceiving serious and incurable cancer (Salmon et al., 1996) and other chronic

Received: 25.12.2007 – Accepted: 02.02.2008

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*This research paper is based on the PhD thesis submitted by the first author Margorit Rita Krespi to the University of Liverpool.
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diseases (Sodergen and Hyland, 2000) as having positive effects. Second, social aspects of adjustment have been understood in terms of whether ESRF and its treatment interfere with social activities and roles, and whether patients perceive social support. Research in cancer shows that social aspects of adjustment are more complex, even to the extent that they involve improvement in interpersonal relationships (Sodergen and Hyland, 2000).

Overall, these findings suggest that the measurement of quality of life with many of the existing measures is unlikely to capture some important elements of ESRF patients' experience. Therefore, it is necessary to examine patients' experience of the effects of ESRF on their lives. Qualitative methods offer a way to understand patients' perspective, such that the findings reflect the ways in which patients normally experience the effects of illness, rather than theoretical or professional assumptions.

There are a number of defining characteristics of qualitative research. First, qualitative designs aim to explore a naturally occurring phenomenon, such as the effects of an illness, within its real-life context from the perspective of the patients (Patton, 1990; Henwood and Pidgeon, 1992; Orford, 1995). Hence, they are naturalistic and aim to obtain the patient's view of a phenomenon (Patton, 1990; Henwood and Pidgeon, 1992; Orford, 1995). Second, qualitative methods are inductive (Patton, 1990); that is, in qualitative research, researchers avoid imposing any *a priori* theoretical assumptions or preconceptions onto the data, and aim to explore and describe a phenomenon in detail, as well as to generate concepts and develop theory inductively (Patton, 1990; Henwood and Pidgeon, 1992; Carr, 1994; Orford, 1995). Third, qualitative researchers aim to understand and describe a phenomenon in terms of all of its complexities and perspectives, and to put themselves in the participants' circumstances and understand their feelings, experiences, and opinions (Patton, 1990). Thus, qualitative research is neutral and empathic. Neutrality refers to the researcher's stance towards the findings, whereas empathy refers to the researcher's stance towards the participants of the study, which conveys interest and caring (Patton, 1990). Last, qualitative research adopts a holistic approach to data collection (Patton, 1990) in order to achieve a better understanding of a phenomenon; that is, it gathers information on each aspect of the phenomenon being studied and focuses attention on subtleties, idiosyncrasies, and contextual issues (e.g. social, cultural, or political factors) (Patton, 1990).

Some studies have used qualitative methods to de-

scribe the effects of illness, involving not only emotional deterioration (Charmaz, 1995; Gregory et al., 1998; Wright and Kirby, 1999), but also feelings of alienation from the body and negative views of oneself (Charmaz, 1983; Charmaz, 1995). Conversely, these effects can also involve reassessment and reevaluation of oneself (Charmaz, 1991), reframing the illness as a new normality (Gregory et al., 1998), and experiencing a better understanding of oneself (Rittman et al., 1993); however, most of these studies have mixed samples, including patients with ESRF and other chronic physical illnesses, and patients being treated with different forms of dialysis, including continuous ambulatory peritoneal dialysis (CAPD). We therefore examined hemodialysis patients' views of the effects of ESRF on their lives using a qualitative methodology, with the intention of avoiding confounding findings due to the use of mixed samples.

METHOD

Sample

In qualitative research, generalization is very difficult to achieve because very detailed and rich data are gathered from a small number of individuals (Miller and Crabtree, 1992). Therefore, in qualitative research the term transferability has replaced generalization. Transferability refers to the ability to use the findings of a study in contexts that are similar to those from which they were originally derived (Henwood and Pidgeon, 1992).

In qualitative research, sampling is purposeful. The rationale behind purposeful sampling is to select participants who can provide detailed information regarding the issues central to the purpose of the research (Patton, 1990).

Our sample in the present study, therefore, was purposeful to ensure that the study explicitly targeted hemodialysis patients whose views were considered relevant (Patton, 1990; Henwood and Pidgeon, 1992). The selection of the type of purposeful sampling was guided by the aim of the study to ensure transferability of the findings to other hemodialysis patients (Henwood and Pidgeon, 1992; Banister et al., 1994). To that effect, we used typical sampling. This sampling method selects participants who can describe and illustrate what is typical of hemodialysis patients (i.e. the key issues that must be considered) (Patton, 1990). Typical hemodialysis patients can be selected through the cooperation of key informants who can help identify what is typical (Patton, 1990). Specifically, a 'typical' hemodialysis

patient was diagnosed with ESRF due to a commonly identified cause (such as diabetes, hypertension, or glomerulonephritis), and were receiving chronic hemodialysis treatment; renal nurses identified such patients from among those attending the hemodialysis ward of a British university teaching hospital and its 4 satellite units. The sampling continued until no new information was forthcoming (Lincoln and Guba, 1985).

In addition to using typical sampling, we also ensured transferability of the findings by being reflexive, i.e. by disclosing assumptions or preconceptions to the readers and describing for them the extent to which the understanding of a phenomenon changed as a result of close engagement with the participants' accounts and their repeated refinement (Stiles, 1993; Banister et al., 1994).

The patients were approached sequentially on study days and asked to consent to being interviewed about their views of their illness and treatment. Of 20 suitable patients that were approached, 16 consented to be interviewed, including 11 from the hospital and 5 from satellite units (11 female, 5 male; mean age: 57 years; age range: 23-77 years). Mean duration of hemodialysis was 4 years (range: 6 months-21 years). Two of the 5 satellite units were in middle-class suburbs and 2 were in inner-city areas. Two patients were employed, 6 were homemakers, 1 was unemployed, and 7 were retired; 5 of the retirees retired because of ill health. Ten patients were married, 4 were widowed, and 2 were single. Exclusion criteria included insufficient understanding of English, and the presence of a medical condition preventing participation, including dementia related to hemodialysis treatment, and blindness.

Data Collection

Qualitative researchers use different approaches to interviewing. We employed the general interview guide approach. In this approach a set of topics and issues are determined in the form of an outline before the interview begins, but the sequence and the wording of the questions depend on the flow of the interview (Patton, 1990). This approach allows for probing and clarifying areas that are not anticipated when the interview protocol was prepared.

Patients were interviewed individually for 60-90 minutes while they were undergoing hemodialysis. They were prompted to describe changes that they experienced in their lives following the onset of their illness. The pace and sequencing of the interview depended on

the patient. The interviewer (RK) encouraged patients to talk in their own way and avoided closed questions. The interviews were audio-recorded and transcribed anonymously.

Data Analysis

In a qualitative study a wide range of theoretical orientations can be followed, which differ in their purpose and the ways in which the qualitative data are analyzed and interpreted (Patton, 1990; Elliott et al., 1999). We based our study on the Grounded Theory (Glaser and Strauss, 1967), which has contributed to the literature of medical sociology and nursing (Miller and Crabtree, 1992). This theoretical orientation aims to develop a theory about the main psychological processes of a phenomenon, which is grounded in the views of the participants being studied (Patton, 1990; Miller and Crabtree, 1992). This also specifies a number of data analysis strategies that have been particularly influential, including a gradual understanding of a phenomenon through a repeated cycle of data collection, a multi-step process of coding the data, and comparative analysis (Glaser and Strauss, 1967; Strauss and Corbin, 1990; Yardley, 1997).

Thematic analysis began in parallel with the interviews. Anonymized interview transcripts were analyzed inductively, following established conventions to ground analysis on the data, rather than on pre-existing ideas (Glaser and Strauss, 1967; Dey, 1983; Patton, 1990). In qualitative research replication is understood in terms of the concept of consensus. We achieved consensus by following established recommendations (Elliot, 1989; Guba and Lincoln, 1989); that is, preliminary analysis by 1 author (RK), based on reading 10 transcripts, was developed following discussion with a second author (PS), who also read the transcripts, and periodic discussion by all the authors. Recurrent patterns were identified, then tested and modified by cycling between additional data and the developing analysis. Procedures are insufficient to guarantee useful findings (Barbour, 2001; Salmon, 2002).

In qualitative research reliability refers to the trustworthiness of data gathered through observations or interviews, and involves helping the reader to understand the data (Stiles, 1993). We demonstrated the trustworthiness of the data by ensuring that sufficient transcript material was provided to illustrate the themes identified in our analysis.

In qualitative research validity refers to the trustwor-

thiness of the analysis, including interpretations and conclusions (Stiles, 1993). The criteria by which we assessed the trustworthiness of our analysis were coherence and theoretical validity (Stiles, 1993). Coherence refers to the comprehensiveness of interpretations, the degree to which the categories fit the data, and the degree to which the categories are meaningfully related to the phenomenon being studied (Henwood and Pidgeon, 1992; Stiles, 1993). Theoretical validity refers to the degree to which the conclusions drawn are connected to theoretical ideas beyond the present study. In addition, we were concerned with its catalytic validity, which refers to the potential of the data and conclusions drawn to influence practice and research (Guba and Lincoln, 1989). The present study's analysis ceased when no further changes emerged from the process and when all relevant texts were accommodated by it. Each category of the final analysis was defined by several patients' data. In the results that follow, illustrative transcripts (in italics) demonstrate the range and commonality of the content of each category. Omitted text is indicated by ellipsis.

RESULTS

Initial attempts to separate the patients' accounts in terms of deterioration versus improvement in life as a result of illness and treatment were unsatisfactory, and probably reflected the authors' previous views. Instead, patients' accounts emphasized other characteristics, including ways of evaluating life, particularly attitudes towards limitations and feelings about changes.

Three general components of life evaluation were identified from the patients' accounts: attitudes towards limitations, feelings about caregivers, and emotional and personal changes.

Attitudes towards Limitations

Awareness of limitations was an important aspect of the patients' experience. All patients reported feeling highly aware of their limitations, which were primarily attributed to physical difficulties caused by ESRF and its treatment, including shortness of breath, weakness, dizziness, and tiredness; however, patients described contrasting attitudes towards them. Most described having lost the ability to perform previous activities: I used to be an active person; now, you just bring them [children] to school, you pick them up, and get back; I feel breathless. In particular, many of these patients were explicit that they were powerless to overcome these limitations: you can't fight it; there's no energy.

The view of limitations as inescapable extended to avoiding situations that were reminders of previous activities or current limitations: as far as going anywhere and doing party nights, I do nothing because I want to have a drink; you don't want to see them all dancing and singing and all that, because you can't do it. This view also extended to blaming external factors, including practical constraints caused by the need to be close to a dialysis center: I've done a good deal of travelling to different places in the world; obviously, this has stopped because I can't move from where I am, and the attitudes of other people, including care staff: I asked to swap [as dialysis day] Christmas day for that being on Sunday, with somebody else. They don't want me to swap. I want to be with my children at Christmas. They say 'you can bring your children here'. I say 'they don't want to sit here for 5 hours.' They want to go home. They have all their presents to play with.

Nevertheless, patients described different ways that they could escape the experience of limitations, particularly by comparing themselves to other people: people are worse than me, that's how you look at it, and adopting a different approach to life: you have to have bad days to have good days; you've got to put up with it.

Several patients described 'getting round' the limitations, particularly by rationing energy: I can't do as much as I used to do. I can do a bit of hovering and sit back; I can do my own washing; I've got to rest; everything you do you got to sit down and have a rest and take it easy; You soon get tired, and making complex special arrangements related to the need for regular hemodialysis treatment: Every year I used to go abroad, but now lots of arrangements have to be made to dialyse 3 times a week, But I got to do it; it's unfair to my wife.

Mixed Feelings about Caregivers

The experience of caregivers was an important aspect of life for many patients; however, patients described contrasting experiences. Caregivers were described as supportive, but patients also recounted negative experiences. Although the view that illness restricts life was almost universal, the aspect that was described as distressing was not always the inability to do things for oneself, but the reliance on others to do them: I used to do a lot of driving, now I'm relying on somebody else; I can't do any driving; I couldn't bring myself back from the hospital, it's not safe; You're not the boss; You just can't accept it. Whereas most patients experienced feelings of dependency, this was perceived differently by different

patients. Some accepted the dependency imposed by the illness and expressed satisfaction with the resulting support from caregivers: she saves my life that girl [daughter] being an angel. She comes up; She does everything for me. Others, in contrast, felt that dependency was imposed by caregivers rather than by the illness: my husband does most of the housework, but even if I attempt to do something he goes mad. He says, 'I don't want you overdoing it. I don't want you doing that'. He wants me to rest all the time. I just accept that. Rather than having a fight I just say OK, and go down and play with the baby.

Caregivers were also described as sources of difficulty and distress. Some were perceived as unsupportive, disappointing, or insensitive: one day she [wife] hates me, the next she loves me; my wife feels sorry but she says 'I'm not a nurse.' Even supportive caregivers gave rise to feelings or fears of being a burden: my wife is going for a fortnight with her daughter. I'd like to go but I don't want to hold her back, and guilt: my mum had to do nearly everything while my husband was at work. He gave up work July this year. That's why he said, 'I have to give up my job to look after you'. I didn't argue with him because I felt guilty about my mum. ...My daughter had a hard life too. She had a lot to do when he was at work. She had to grow up before her time, in that sense..... I felt guilty in some way.

Emotional and Personal Changes

Emotional changes were also an important component of the patients' experience. Patients described feeling that I lost my confidence, or that There's fear of the future..., and when I look ahead, I'm going downwards. In addition to poor concentration, several patients described being angry, irritable, bored, agitated, in bad temper, down or depressed, even to the point that, You feel as if you want to commit suicide. You don't know what to do. I feel like that because you sit down and feel sometimes like taking some pills. I feel so alone.

In addition to the deterioration in emotional state, patients recounted worsening aspects of character or personality. These included becoming more selfish: I don't listen to people; I want to tell people about my problems; there is no energy to cope with others' problems; others' problems seem very trivial, and less compassionate I've gone harder towards life; things that you've got to get done to you, insulin, putting the needle in. I don't like them, but also —'not very pleasant to live with or feeling sorry for yourself.

In contrast, other accounts described improved aspects of character. These included becoming more considerate: I watch more what I say to people; I don't want to hurt anybody; I want to keep each other happy; I became more considerate about him [husband] and his feelings, and having a better understanding of other people: I'm experiencing limitations myself really. For the first time it's giving me a good deal of sympathy for other people with other limitations, perhaps different than mine; I have a better understanding now, but also feeling closer to people: dialysis is the focus of our life; it brought us together; my husband is very supportive.

DISCUSSION

The present study has provided a detailed systematic account of the ways in which hemodialysis patients evaluated their lives. Some of the findings provide details about how the psychological processes that have been previously reported operate in practice, which clinicians and researchers need to understand; however, some findings cannot readily be explained according to existing ideas.

Patients evaluated the impact of their disease and treatment in terms of their experience of limitations, their feelings about caregivers, and personal and emotional changes.

Attitudes towards Limitations

The main component of the patients' experience was awareness of the illness and the limitations it imposed. This reflects the assumption inherent in the constructs of perceived intrusiveness and perceived control; a chronic illness damages and constrains patients' lives. Experience of limitations and a sense of loss of existing roles have been reported in other chronic illnesses, such as ulcerative colitis and rheumatic arthritis (Wiener, 1975; Kelly and Field, 1996; Kelly and Dickinson, 1997), as well as in ESRF (Gallo et al., 1992; Gregory et al., 1998; Kimmel, 2002). Interestingly, however, diverse attitudes towards limitations were described by the patients in the present study, which have not been previously reported. The patients' experience defined a continuum. At one end, limitations were experienced as inescapable obstacles. On the other hand, there was the feeling that the limitations could be overcome by, for example, making special arrangements, constructing a new lifestyle, or changing one's attitude. There was also the tendency to avoid situations that reminded them of previous leisure activities and to blame limitations on external factors. As

the awareness of limitations is an important aspect of patients' experience, the different ways in which limitations are managed are, therefore, likely to be very important influences on adjustment.

Mixed Feelings about Caregivers

As expected, caregivers were frequently described as supportive; however, important negative experiences of caregivers also emerged. 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. Inherent to these feelings was that the patients aimed to maintain some autonomy and ability to look after themselves. In fact, although most patients experienced feelings of dependency, for some patients dependency was imposed on them by their caregivers, rather than by the illness itself. Patients' sense of the burden of care giving has been previously reported in chronic disease (Charmaz, 1983). The present study extends this finding by identifying a wider spectrum of both positive and negative aspects of patients' experiences of their caregivers. In addition to its positive effects (Kimmel et al., 1995a; Elal and Krespi, 1999), according to quantitative research it is well recognized that social support can have adverse effects on adjustment and compliance with treatment in dialysis patients (Palmer et al., 1983; Boyer et al., 1990). The present findings provide detailed information on negative aspects of supportive relationships, which suggest mechanisms by which social support is likely to compromise adjustment and compliance in ESRF. Patients who reported negative experiences with their caregivers are likely to be at risk of adjustment difficulties because of the importance of social support in maintaining emotional well-being and compliance (Christensen et al., 1992; Kimmel et al., 1995b); therefore, clinical consultations need to target these issues.

Emotional and Personal Changes

Patients in the present study described emotional deterioration, which is consistent with previous reports of anxiety and depression (Nichols and Springford, 1984; Kimmel et al., 1995b; Cukor et al., 2007), feelings of uncertainty (Gregory et al., 1998), and sadness, sorrow, and loss (Wright and Kirby, 1999) in hemodialysis patients; however, deterioration was experienced by the patients in the present study not simply as the addition of emotional problems, but as worsening

of fundamental aspects of character or personality, a process that has not been previously reported.

Some changes in character were, however, positive. Previous studies report that some hemodialysis patients experience a sense of improved understanding of themselves (Rittman et al., 1993) and that other chronically ill patients experience positive inner change (Herzlich, 1973; Radley and Green, 1987); however, our patients described improvements in social awareness and sensitivity. They felt that they had become more considerate, developed a better understanding of other people, and had become closer to them.

The experience of these positive changes in character indicates that the effects of ESRF on life do not necessarily involve loss, but can involve the attachment of positive meaning to the illness in a similar way as has been described in cancer patients (Taylor, 1983; O'Connor et al., 1990; Salmon et al., 1996) and in other chronic diseases (Sodergren and Hyland, 2000). The importance of the subjective meaning of chronic illness, including ESRF (McGee and Bradley, 1994; Sharpe and Curran, 2006) has been previously reported; however, the present findings showed ways in which meaning was attached to ESRF. Attachment of positive meanings to ESRF may represent an important mechanism by which healthy adjustment is fostered.

The methodology of the present study provided a detailed account of how hemodialysis patients evaluated their lives. The present findings highlight for clinicians several ways of evaluating life that are likely to compromise adjustment. These included the perception that one has failed to 'get round' limitations, the experience of caregivers as a source of distress and difficulty, the feeling that illness has worsened one's character, and the failure to derive a positive meaning from ESRF. Clinicians might use qualitative findings to inform their interventions for promoting better adjustment. Therefore, the present findings contribute to an evidence-base for patient-centered care of hemodialysis patients.

Overall, these findings highlight the value of undertaking qualitative research of hemodialysis patients in order to identify specific targets for clinical practice. Our findings are based on typical hemodialysis patients, and, therefore, are transferable to these patients only. Further qualitative research can explore the transferability of these findings to other groups of haemodialysis or ESRF patients. To enhance their clin-

ical practice clinicians require evidence, not just the range of patients' views, but their frequency as well. Nevertheless, qualitative research cannot provide such generalizable information; therefore, future quantitative research need to develop a questionnaire based on the present qualitative findings in order to quantify the extent of each view, and to examine the clinical utility of these findings in improving poor adjustment. This ques-

tionnaire should also be validated using established generic and ESRF-specific measures of emotional distress and adjustment. Moreover, the present findings are not transferable or generalizable to other cultural and religious groups. Research to determine the clinical utility of these findings should include examination of its relevance to different cultural and religious groups.

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