

Shift in paradigm: understanding adjustment of dialysis patients

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ABSTRACT

End stage renal failure (ESRF) and its treatment can lead to adjustment difficulties. However, the extent of these difficulties is not known. Adjustment is a complex and multidimensional construct. In general beliefs about illness and its treatment influence adjustment but the findings are inconsistent. This is probably because adjustment and beliefs have been defined in a variety of ways based on professional or theoretical views. One possible way of establishing a standard approach to defining adjustment and beliefs is to be guided by patients' own views. Qualitative studies identify ways of evaluation of life and beliefs about ESRF and its treatment that have not been identified by quantitative studies. These findings can be considered as patient-derived targets for psychoeducational programs or clinical practice for ESRF patients. However, qualitative research cannot provide evidence about the frequency of patients' beliefs and ways of evaluation of life. Therefore, questionnaires have been developed on the basis of qualitative findings. These helped to examine the utility of the findings for clinical practice, and understand the relationship of quality of life with beliefs. More research is needed to investigate how the findings on these questionnaires converge and diverge with those on existing generic and/or ESRF specific quality of life and beliefs measures. (*Anatolian Journal of Psychiatry* 2017; 18(3):292-299)

Key words: ESRF, adjustment, beliefs, qualitative research, quantitative research

Paradigma değişimi: Diyaliz hastalarının uyumlarını anlama

ÖZET

Son dönem böbrek yetmezliği (SDBY) ve tedavisi uyum sorunlarına yol açabilir; ancak, bu sorunların kapsamı bilinmemektedir. Uyum kavramı karmaşık ve çok boyutlu bir kavramdır. Genel anlamda hastalık ve tedavi ile ilgili inanışlar uyumu etkilemesine rağmen, bulgular tutarsızlık göstermektedir. Bu tutarsız bulguların nedeni, olasılıkla bu inanışların profesyonel veya kuramsal görüşlere dayalı olarak tanımlanmış olmasıdır. Uyum ve inanış kavramlarını tanımlama konusunda standart bir yaklaşıma ulaşabilmek için hastalarının kendi görüşlerinden yararlanmak olası bir yol olabilir. Nitel araştırmalar yaşam değerlendirme yolları, hastalık ve tedavi ile ilgili inanışlar konularında nicel araştırmaların ulaşamadığı bulgulara ulaşmaktadır. Bu bulgular psikolojik eğitim veya klinik görüşmelerin hedefleri olarak düşünülebilir. Bununla birlikte, nitel araştırmalar hastaların inanışları ve yaşam değerlendirme yollarının sıklığı hakkında kanıt sağlayamaz. Böylelikle nitel bulgulara dayalı anketler geliştirilmiştir. Bu anketler bulguların klinik uygulamalar için yararlarını ve yaşam kalitesi ile inanışlar arasındaki ilişkiyi incelemeye yardım etmektedir. Bu anketlerin halen var olan genel ve/veya SDBY'ye özgü yaşam kalitesi ve inanış anketleri ile ne şekilde örtüştüğü ve farklılaştığı açısından incelenmesine yönelik daha fazla araştırmaya gerek duyulmaktadır. (*Anadolu Psikiyatri Derg* 2017; 18(3):2932-299)

Anahtar sözcükler: SDBY, uyum, inanışlar, nitel araştırma, nicel araştırma

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The treatment of end-stage renal failure (ESRF) involves dialysis treatment or transplantation as well as changes in lifestyle including diet and fluid restrictions. ESRF and its treatment require adaptational demands in patients' life. These adaptational demands which could be understood on the basis of the construct of adjustment means that patients are required to change their behavior to meet the demands brought by ESRF and its treatment. This article aims to review the literature in relation to not only theoretical aspects of adjustment, but also to some psychosocial factors that are related to adjustment in dialysis patients.

Adjustment has been defined in various ways which are based on different postulations about what is important in adjustment. Ways of defining adjustment involve whether or not the patients experience psychological problems or difficulties in functioning. Adjustment has been also defined globally by for example, in terms of overall quality of life. However, quality of life itself is a multidimensional construct¹ defined in various different ways. Some authors have defined it through using seemingly objective criteria such as demographic, medical or economic criteria. Others have defined it in subjective terms including the ways in which patients evaluate their own life. This in turn has been defined in different ways. One way of evaluation of life has been undertaken in terms of global life satisfaction and happiness. Life satisfaction refers to people's opinion of life on the basis of personal norms, whereas happiness refers to the experience of positive mood as opposed to negative mood.² Another way involves defining life evaluation in terms of specific subdimensions including physical, role, social and emotional dimensions.¹

Consistent evidence shows that depression is the commonest psychological problem.³ Although depression levels of these patients are greater than that of general population,³ the prevalence of depression varies across different studies. Estimates have ranged from 15-61%.³⁻⁵ Similarly, as compared to patients with other chronic illnesses, patients report higher levels of anxiety.⁶ However, levels of anxiety also vary across different studies. These levels vary between 13% to 87%.^{3,5,7} Studies also show that quality of life is poor^{7,8} and its level is lower than that of general population.^{7,8}

There is some evidence that ESRF leads to adjustment difficulties. However, findings have been contradictory regarding the extent of these

difficulties partly due to the differences in the characteristics of the samples used such as duration and type of treatment and different approaches that investigators have taken to defining and measuring adjustment. There has been extensive research on a wide range of psychosocial factors including social support and beliefs in order to explain adjustment difficulties.

There are a number of different operational definitions of social support. It has been operationalised on the basis of perceived availability of social support, illness-specific social support or satisfaction with social support. Other operational definitions include family support which has been in turn operationalised as the extent of family cohesion, expressiveness and conflict.

The association of social support with adjustment has been widely examined. However, the findings have been inconsistent. Evidence shows that low social support is associated with quality of life⁹ and low satisfaction with life.¹⁰ Similarly, high social support has been associated with low depression and/or better adjustment.^{11,12} By contrast, other studies suggest that social support can also have a negative effect on adjustment¹³ or no effect on depression or anxiety.¹⁴

Social support has not been consistently related to adjustment. These results are partly due to various approaches to defining and measuring it. Moreover, different types of social support may be beneficial in coping with different demands. Although emotional support is generally beneficial for coping with different stressful events, instrumental and informational social support may help to cope with specific needs of a particular event.¹⁵ Therefore, a more consistent conceptualisation of social support is necessary before reliable and valid conclusions can be drawn regarding its effects on adjustment. Another reason for these inconsistent findings is that social support not only has positive but also negative effects on adjustment.

Recent research examines the ways in which patients' beliefs influence their adjustment to illness. There are several different models of beliefs, which explain their effects on adjustment. Numerous studies have therefore examined these effects. The most impactful theories will be reviewed along with the findings of studies that examined the effects of beliefs postulated by these theories on adjustment.

Social Learning Theory¹⁶ postulates that an

individual will more likely show a particular behavior if he/she believes that it will result in desired outcomes. One construct of this theory, locus of control refers to the notion that some outcomes result from one's own behaviours (internal), and others result from external sources. In health related contexts, it refers to as health locus of control¹⁷. The main criticism for these constructs involved the notion that internal-external split is too simplistic.¹⁸ Therefore, a multi-dimensional approach was taken to understand these constructs. This consisted of internal (IHLC) and external health locus of control (EHLC) including chance (CHLC) and powerful others locus of control (POLC).¹⁹

A large number of studies have investigated the relationship of health locus of control with adjustment and findings suggest that this facilitates adjustment. Specifically, high IHLC is related to low depression^{20,21} and anxiety^{22,23} and good quality of life^{22,23} specifically good physical²⁴ and mental quality of life.²⁵ Evidence also suggests that this predicts depression.²⁶⁻²⁷

Conversely, high EHLC is related to quality of life,²⁴ high emotional distress,²⁸ and high depression.^{23,24} However, these relationships have not been consistent across different dimensions of quality of life but have concerned some dimensions including mental health, general health perception and emotional role functioning.²² Relatedly, another study found that when levels of social support were satisfactory EHLC was associated with low depression.²⁰

Other studies have examined the relationship of specific types of EHLC with adjustment. Evidence suggests that high significant others EHLC is related to poor physical quality of life,²⁴ good general quality of life,²⁵ high depression²³ and high anxiety,²³ doctors EHLC is related to good quality of life²² and high powerful others EHLC and chance EHLC are associated with poor quality of life.²² However, these relationships have not been consistent across dimensions but have concerned some dimensions including mental health, general health perception and emotional role functioning.²² However, other studies have showed no relationship of health locus of control with quality of life.^{3,29}

The Learned Helplessness Theory³⁰ postulates that depression, helplessness and hopelessness are related to the notion that whether or not individuals believe that they can influence future outcomes. The Theory of Planned Behavior³¹ postulates that an individual is more likely to show a particular behaviour if he/she intends to

undertake that behaviour. In turn, this depends on attitudes about showing the behavior and subjective norms. Perceived control influences behaviour through its influence on intentions, although it can also directly influence behavior whereas internal factors (such as skills) and external factors (such as opportunity) influence perceived control.³¹ Common to Learned Helplessness Theory and Theory of Planned Behavior is the concept of perceived control which refers to the belief about the amount of control one has over a given event.³²

A small number of studies have examined the relationship of perceived control with adjustment. When patients with ESRF perceive greater control over their life, their illness and its treatment they report better adjustment.³³

In general, findings in relation to perceived control or health locus of control have been inconsistent. The variance explained by either of these constructs is small. For example, it was found that 5.5% of the variance in depressive symptoms was explained by locus of control.²⁴ A problem with these constructs is that these are very general. A study which examined patients' responses to an intervention targeting feelings of control concluded that patient control over medical treatment seems to be a theoretical and professional assumption.³⁴ This suggests that perceived control or health locus of control may not necessarily reflect dialysis patients' own experience.

The Health Beliefs Model (HBM)³⁵ postulates five factors that determine compliance: perceived susceptibility to illness; perceived severity of illness; perceived benefits of treatment; perceived barriers to treatment; and cues to action.⁵¹ Accordingly, patients comply with treatment when they perceive the illness as serious, they feel vulnerable to it, they perceive a high number of benefits of treatment and a small number of barriers.³⁵

Although no recent study has investigated the relationship of health beliefs with adjustment, a few studies have showed that health beliefs are not related to depression or anxiety³⁶ but only high perceived severity is associated with high satisfaction with life.³⁷

Overall, the HBM has been criticized on the basis of the notion that behaviour is not merely based on a rational evaluation of options and likely outcomes³⁸ and that other beliefs may influence health and illness-related behaviors.³⁹ Moreover, beliefs postulated by the HBM are

very general. Patients are likely to hold beliefs about illness and treatment that are very specific.³⁸

Social Cognitive Theory³² postulates that a particular behavior is the result of a self-regulatory process involving a reciprocal interaction of environmental influences with three cognitive variables. These include situation outcome expectancy; outcome expectancy; and self-efficacy.³² Situation outcome expectancy refers to the perception that a specific behavior is harmful whereas outcome expectancy refers to the perception that a particular behaviour is likely to produce some beneficial outcomes. On the other hand, self-efficacy refers to the belief that an individual feels confident about performing health-related behaviors.

A few studies have investigated the relationship of self-efficacy with adjustment. Evidence suggests that there is a positive relationship between self efficacy and quality of life.⁴⁰ The construct of self-efficacy appears to be important because it has the potential to determine the types of behaviours that one will choose or avoid, and how much effort one will put on an activity and the amount of persistence when he/she faces difficulties. However, self-efficacy is defined in general terms. This may therefore limit its clinical utility.

The Self-Regulatory Model of Illness (SRM)^{41,42} is developed through interviews with patients with chronic physical illnesses, and postulates that each patient has his/her own views regarding identity, cause, consequences, timeline and cure or controllability of his/her illness.⁴¹⁻⁴³ Identity includes label or nature of the illness (such as signs and symptoms of a particular illness). Cause refers to factors both biological and psychosocial factors that can lead to an illness. Consequences refer to perceptions about effects of illness. These can be both long and short-term. Timeline refers to how the illness is perceived including acute, episodic or chronic.⁴⁴ Cure or controllability refers to beliefs about whether or not and how patients cope, recover or manage one's illness.⁴³ The SRM conceptualises illness as a problem and assumes that people make a decision about health and illness by engaging in three cognitively and emotionally interactive processes including forming a cognitive representation of illness, developing and implementing a method of coping, and appraising the outcome and the effectiveness of this method.⁴⁵

Some studies that have been reviewed above

can be considered as already researching the effects of the dimension of control postulated by the SRM.⁴⁶ The constructs that are comparable to this component are self-efficacy, perceived control, locus of control and perceived benefits of and barriers to treatment.⁴⁶ Other studies which adopted the framework of the SRM will be reviewed here.

Studies have shown that there is a relationship between the dimensions of this model with emotional well-being and quality of life. Some studies have shown that most dimensions are related to quality of life⁴⁷ and depression.⁴⁸ Other studies have shown that only some dimensions are related to emotional well-being and quality of life. High identity, consequences and control are related to low emotional well-being,⁴⁹ low understanding illness and high emotional consequences are related to high anxiety, low control, high timeline and high emotional consequences are related to high depression,⁵ and high identity is related to physical and emotional wellbeing.⁹

The postulation of the SRM that each patient will have his/her own ideas about components of illness highlights the model's efforts to acknowledge the variation in beliefs across patients and therefore, this model reflects patients' ideas on their illness and its treatment more than do other theoretical models. Indeed, its dimensions explained a high variance in emotional well-being and quality of life. For example, timeline, control and emotional consequences explained 15 to 31% of the variance in quality of life.⁵⁰ Another study⁴⁹ showed that symptoms, consequences and control explained 17 to 51% of the variance in quality of life. However, some evidence raises questions about the validity of its dimensions in type 2 diabetic patients,⁵¹ although not in dialysis patients.

Overall, social support and beliefs have not been consistent correlates of adjustment. However, beliefs have been more consistent correlates of adjustment than social support. Nevertheless, effects of beliefs on adjustment vary across studies. Moreover, the variance explained in outcomes by beliefs has been small except for the dimensions by the SRM.

There is therefore, little evidence to suggest that a particular model should be preferred over others and that beliefs should be measured in future research on the basis of that model. An alternative way of establishing a standard approach to the conceptualization of beliefs is to

be guided by patients' experience: that is, to define and measure beliefs in ways that reflect patients' own thinking. Similarly, quantitative research aims to show whether or not patients experience adjustment difficulties by using measures that defined *a priori* what is important in adjustment. The results have been inconsistent and therefore of limited clinical value. The reasons for these inconsistent findings include different approaches taken to measuring adjustment and defining dimensions of life in very general terms. Therefore, an alternative way of establishing a standard approach to the conceptualization of adjustment is also to be guided by patients' experience:

A possible way of examining the beliefs that patients hold and the way they experience life is to undertake qualitative research. Qualitative evidence suggests that ESRF and its treatment bring a number of changes or restrictions to patients' life including physical and social restrictions, changes in lifestyle and routines, sexual problems, communication difficulties and losses related to roles and employment.^{52,53} There is also confinement or restriction in life, social isolation and becoming a burden to others.^{52,54} Social isolation is triggered by some feelings including feelings of being discredited, embarrassed, ignored and devalued.⁵⁴ ESRF patients' emotional wellbeing is also influenced by their illness in that they report experiencing mood swings and feelings of uncertainty, anxiety, depression and guilt.^{52,53}

Qualitative evidence suggests that ESRF and its treatment do not merely lead to emotional deterioration but that ESRF also influences aspects of patients' personality. ESRF can result in negative self-definitions for example, feeling 'less than a human',⁵⁴ becoming more selfish and less compassionate,⁵⁵ feeling that one's identity is dominated⁵³ and feeling that life is organised around medical treatment.⁵⁶

Adjustment following a chronic physical illness does not merely consist of negative changes or disruption. For example, lifestyle, goals and activities are modified in such a way that ESRF and its treatment is accommodated into daily routine, and integrated into personal identity.⁵³ Patients report reassessing and re-evaluating themselves,⁵⁷ redefining or reframing their illness as a new 'normality',⁵² focusing on new possibilities such as having a job or a transplant,⁵⁶ and using humour and distraction⁵³ or hoping.^{52,53}

Illness can also give a new meaning to life in that

ESRF patients report having a better understanding of themselves, experiencing a changed relationship with the dialysis machine such that it feels 'a part of me' and such that the dialysis unit feels like 'being at home',⁵⁶ becoming more considerate and having a better understanding of other people.⁵⁵ ESRF also impacts on social relationships. Patients believe that their carers provide support but they also present themselves as sources of distress and difficulties. This finding provides mechanisms for the negative relationship of social support with adjustment among ESRF patients.⁵⁵

Qualitative research has shown that ESRF can be attributed to different factors. Patients identified a number of causes of ESRF such as heredity, complications at birth, high blood pressure, infections, stress, lack of care and inadequate medical care.⁵⁸ Patients perceive aspects of their treatment in idiosyncratic ways. For example, patients with ESRF test their dietary and fluid restrictions in a pragmatic way in order to examine how well these restrictions work in real life situations⁵² and get round these restrictions by for example, sucking ice-cubes or candy and using smaller plate sizes.⁵⁶ Another study⁵⁸ found that patients could not identify clear mechanisms on how dietary control worked. In the same study, patients not only viewed haemodialysis as 'cleansing' but also believed that haemodialysis would purge the body of food or drink that is not on diet. They also viewed different aspects of treatment including haemodialysis and dietary restrictions as imposed by doctors and as dominating life. Same authors in another study⁵⁹ found that patients perceived a wide range of specific challenges to diet and fluid restrictions. Of particular importance, these included being with others, the perception of haemodialysis as compensating for non-compliance with diet, and emotional challenges such as distress.

In conclusion, existing psychological theories can help to make sense of some findings but other findings go beyond these theories. Therefore, these identify patient-derived targets for psychoeducational programs or clinical practice for ESRF patients. Clinicians need evidence on both the range of patients' beliefs and ways of evaluation of life and their frequency to improve their consultations with patients. However, qualitative research cannot provide that kind of information. Therefore, questionnaires have been developed on the basis of qualitative findings,^{58,60} which helped quantify different views, examine their utility for clinical practice,

and understand the relationship of quality of life with beliefs. More research is needed to investigate how the findings on these questionnaires converge and diverge with those on existing generic and/or ESRF specific quality of life and beliefs measures. More importantly,

these findings cannot be transferred or generalized to other cultural groups. Therefore, more research is required to establish the utility of these findings for clinical practice targeting different cultural groups.

The main argument presented in this review stems largely from my PhD thesis entitled 'Patients' perceptions of their chronic physical illness, its treatment and its effects: Towards patient-derived interventions' (Krespi, 2001) and I thank Professor Peter Salmon for his comments and suggestions.

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