

## Minireview

# Identifying Depression in South Asian Patients with End-Stage Renal Disease: Considerations for Practice

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## Key Words

Depression · End-stage renal disease · South Asians · Measurement · Screening

## Abstract

Depression is a prevalent burden for patients with end-stage renal disease (ESRD) and one that is under-recognized and consequently under-treated. Although several studies have explored the association between depression symptoms, treatment adherence and outcomes in Euro-American patient groups, quantitative and qualitative exploration of these issues in patients from different cultural and ethnic backgrounds has been lacking. This review discusses the methodological issues associated with measuring depression in patients of South Asian origin who have a 3- to 5-fold greater risk of developing ESRD. There is a need to advance research into the development of accurate screening practices for this patient group, with an emphasis on studies utilizing rigorous approaches to evaluating the use of both emic (culture-specific) and etic (universal or culture-general) screening instruments.

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## Introduction

End-stage renal disease (ESRD) is a growing public health problem [1] and one that has a significant impact on the lives of patients [2]. There are multiple sources of stress associated with the loss of kidney function and reliance on a multifaceted treatment regime. The reliance

upon dialysis is one of these stressors, with other adjustments including changes in family roles, mobility, dietary constraints, medication effects, worry over the dependency on treatment and fear of death [3–5]. Furthermore, depression is a prevalent problem in patients with ESRD. The Diagnostic and Statistical Manual of Mental Disorders 4th edition (DSM-IV) defines major depressive disorder as the loss of interest or pleasure for weeks accompanied by a constellation of 5 or more psychological, behavioural and somatic symptoms, and classifies depression as a disease which is primarily generic or neurochemical in aetiology [6]. The symptoms of depression include depressed mood, sleep disturbances, fatigue, reoccurring thoughts of death or suicide and a lack of energy. In chronically ill populations, it is estimated that depression accounts for half of the identified psychopathology [7], which can lead to increased clinical and psychological morbidity due to reduced compliance with treatment and reduced functional levels [8]. Indeed, in ESRD, several studies have demonstrated the association between depression symptoms, quality of life (QoL) [9, 10] and survival [11–15].

Although the prevalence of depression in ESRD is largely unknown, its impact on treatment outcomes has made it critical to advance the psychological assessment of patients. The assessment of depression typically involves self-complete screening instruments and the use of clinical diagnostic interviews, either of which are administered according to diagnostic classification systems such as the DSM-IV or the International Classification of Diseases (ICD-10). Screening instruments typically employ cut-off scores which can be used to characterize a patient's symptoms as mild, moderate or severe in terms of depressive symptomatology. In chronically ill populations, the accuracy of screening instruments is, however, limited due to 'criterion contamination', which is the overlap of somatic symptoms associated with the underlying medical illness and depressive symptomatology [2, 8]. Whether or not screening and diagnostic schemes should remove overlapping symptoms is a topic of much debate, and there is limited evidence to suggest that the cognitive and somatic symptoms associated with depression can be separated from affective and behavioural components [16–18]. Nonetheless, several studies in the renal field have now reported on the clinical diagnostic accuracy of screening instruments such as the Beck Depression Inventory (BDI-II [19]) for this patient group, finding that the prevalence of depression in ESRD ranges from 20 to 30% and indeed contributes to adverse clinical outcomes, although precise measurement remains a pertinent issue [2].

The advances made in the clinical understanding of depression symptoms in ESRD will, however, benefit some patients more than others. Research in this area has, in the main, focused on the experiences and development of screening practices for patients from 'white Euro-American' backgrounds, which remains a significant issue in terms of generalizability. This may be because there are unique barriers that prevent clinicians from exploring the concerns and symptoms of patients from other cultural and ethnic groups. The aim of this article is to discuss the issues surrounding screening and diagnosis of depression in South Asian patients (patients originating from the Indian subcontinent including India, Pakistan, Bangladesh and Sri Lanka) with ESRD.

### Prevalence of ESRD in South Asians

Whilst ESRD is a recognized health problem across the world, its prevalence in South Asian populations is unknown because of insufficient national and international registries and poor government policies to support patients from developing countries [20]. It is however clear that within the United Kingdom (UK), there is a significantly higher incidence of ESRD in South Asians [21, 22]. It is estimated that South Asians are 3 to 5 times more likely to develop ESRD when compared to white Europeans [23–26]. This has often been explained

in terms of the greater prevalence of diabetes in South Asians, which is the most common cause of ESRD [27], making this group more vulnerable to diabetic nephropathy than other minority and European groups, often despite uniform medical care [25, 28, 29]. Consequently, there is a high demand for renal transplants amongst South Asians in the UK, although the supply of suitable kidneys is low, as is the rate of transplantation [30]. It is however encouraging that studies conducted in both the UK and the United States report that survival rates in ESRD are not compromised due to ethnicity. In fact, several studies have reported better survival rates in South Asian dialysis patients [31–34]. Although the determinants of better survival in South Asians are not fully understood, factors such as higher mean Kt/V have been associated with more favourable outcomes [34].

### Depression in South Asian Patients with ESRD: Challenges for Accurate Screening

To our knowledge, there are no published studies on the prevalence of depression in haemodialysis patients of South Asian origin. A study carried out with patients receiving peritoneal dialysis in India reported that 65% of patients experienced some depressive symptoms, and that 19% of patients had severe depressive symptomatology [35]. The dearth of research into the prevalence of depression in this patient group is coupled with few qualitative investigations into the attitudes, thoughts and feelings of South Asian patients toward renal care, which makes it difficult to understand the range of factors that impact treatment adherence and outcomes, and to make selected comparisons with other groups. There is however evidence to suggest that QoL, which is an important propensity of patient outcomes, is significantly lower in South Asian patients receiving renal replacement therapy when compared to their caregivers [36], and other minority and white Euro-American patients [37]. Specifically, South Asian patients are more likely to view ESRD as a social burden, even when successfully treated by transplantation [37]. Differences in QoL appear to be unrelated to treatment modality, treatment adequacy and comorbidities [37]. So whilst South Asian patients may not be disadvantaged in treatment outcomes, as suggested by quantitative investigations, there may be differences in patient experiences that impact psychological well-being – an area that has been largely ignored in the renal literature.

#### *Language Barriers: Issues with Translation and Interpretation*

There are several reasons for the scarcity of research into the psychological well-being of South Asian patients with ESRD. First, there are often language barriers which make it difficult for clinicians and researchers alike to explore the concerns and symptoms of patients, and may indeed lead to misinterpretations of patient complaints [38, 39]. Of course, one way to advance screening of depression symptoms would be to undertake the translation of validated instruments to meet the linguistic needs of the South Asian community within the UK. Translation is however not without its challenges. Hussain-Gambles et al. [40] propose that studies utilizing translation and interpretation are often expensive and time-consuming, making them less attractive for funding. Where translation and interpretation is available, accurate exploration of experiences may be limited by several factors, including culture-specific idioms of distress. Western idioms used to describe psychological distress may not readily translate into other languages. This may result in patients endorsing certain items less frequently because they cannot relate to the language used, which is not the same as being ‘symptom free’. Krause [41] reported on a group of South Asians in Bedford, UK, originating from Punjab in India and described the occurrence of the ‘sinking heart’, a culture-bound idiom used to describe specific somatic symptoms. Whilst these symptoms were similar to the Western conceptualization of stress, the ‘sinking heart’ was seen as a culture-bound

syndrome that resulted from a combination of social, physical and emotional factors. Consequently, Bhui et al. [42] suggest that translators and interpreters must be equally competent in both the source and second language and understand the semantic range of both languages, whilst being sensitive to variations in cultural understandings of distress. Edwards [43] further suggests that translation can be facilitated by the translator being a native speaker in the target language and fluent in the language of the text to be translated.

There are also disparities in the quality of translation undertaken in studies where scales have been used across cultural and ethnic groups. Translation should be an iterative process, involving both forward and back translation to ensure face and content validity. However, there are marked differences in the use of forward- or backward-only translation with mono- or bilingual tests of accuracy [44]. Poor translation methods are often accompanied by a lack of reporting on the validity of translations, with sensitivity and reliability analyses being undertaken without confidence in the conceptual equivalence of scales for use across cultures [42]. This results in the limitations of measures being advanced without providing confidence in the validity of the translated scales. Criterion validity, for example, cannot then be tested. Different constructions of psychological distress across cultures may well have clinical implications which undermine the precise assessment of conditions such as depression. Conducting and evaluating the process of translation needs to be the core aspect of the research design and reporting, without which it will be difficult for professionals to select appropriate instruments to screen for distress in different patient groups.

For a vast number of patients, translated scales, at least within their self-complete format, will not be suitable, and patients will require the use of interpreters in the completion of the scales. Feehally [45], for example, states that 25% of South Asians aged over 65 years living in Leicester, UK, cannot read or write in their native language or English. The use of interpreters to communicate with patients also requires a number of considerations. In a clinical setting, interpreters need to translate the patient's narrative promptly, leaving little time for considering emotional components of language, attitudes and beliefs, which play a vital role in informing clinical interpretations and treatment of symptoms. Furthermore, the presence of an interpreter may hinder the development of an empathic relationship between clinicians and patients, with the non-verbal aspects of communication often being lost when communicating through an interpreter [46]. There may also be variations in how interpreters view their roles, with research suggesting that for some, the role is related solely to accurate communication of information, whilst others view cultural advocacy, sensitivity and social support as fundamental components [47] and factors which influence the assessment of mood. It is also necessary to be aware of cultural tensions between patients and interpreters that influence willingness to disclose symptoms [46]. So whilst translation and interpretation services are undoubtedly useful in clinical settings, research is still lacking in specifying the optimal conditions for ensuring that vital aspects of communication are not lost or misinterpreted through such modes of communication with patients. Studies undertaking the task of translating screening instruments for use in the South Asian ESRD population need to pay due attention to the process of translation and on reporting key information that will allow professionals to make informed decisions in how best to assess the psychological requirements of patients.

### *Conceptual Issues*

It is also highly plausible that there will be differences in the meaning attributed to symptoms of depression in cultures where there are no linguistic equivalents for the term [39]. Indeed, the way patients conceptualize their distress is predicative of not only symptom presentation [48], but also help seeking behaviour [49, 50]. Whilst the beliefs of South Asians within the UK may be influenced by the host society, culture-specific beliefs are also important in understanding physical and mental illnesses. Several studies have found that although

South Asians may be aware of the so-called psychosocial features of depression, they do not favour a biological model of mental illness, which is the core of the DSM-IV and ICD-10 criteria [51–55]. Furthermore, South Asians are more likely to see depression as the result of worry, whereas white Euro-Americans have been found to attribute depression to hopelessness and low mood [54].

The literature on mental health attributions in South Asians has consistently shown that ‘spirituality’, ‘karma’ and ‘God’s will’ are often advanced to help explain medical and psychiatric illness [39, 53, 56, 57]. In a clinical study of Canadian South Asian Punjabi-speaking women with breast cancer, Gurm et al. [58] found that patients predominantly made sense of illness in the context of spirituality. Spirituality provided meaning to illness, often in light of cancer being seen as part of a person’s ‘karma’ or ‘punishment’ for sins. Nonetheless, spirituality offered a positive framework for coping through methods such as prayer. These findings have been replicated with other clinical groups including patients with coronary heart disease (CHD). South Asian patients with CHD encompass biological causes in their explanations of CHD, but spiritual factors also form a core part of illness attributions [59]. More recently, a survey of South Asians in the United States found that whilst 88% of respondents favoured the belief that mental illness is a medical problem, there was stigma attached to seeking professional help, with South Asian patients preferring to turn to close family and friends for support [60]. Seeking help for psychiatric issues can be seen as a sign of weakness or as going against ‘God’s will’, and openly disclosing illness may have broader social consequences for the family [61]. There may also be worry over being misunderstood by health professionals [50]. The meaning attributed to psychiatric symptoms thus varies across different cultural and ethnic groups, and many authors have expressed concern over the universal applicability of the Western model of mental conditions [62–64]. In practice, this means that screening instruments must capture culture-specific idioms of distress, and clinicians need to be aware of barriers that inhibit patients from freely disclosing their symptoms.

#### *Somatization*

A further challenge for clinicians in identifying psychiatric comorbidities pertains to differences in symptom presentation. Due to multiple cultural variants in the expression of distress, striking differences are found in symptom presentation cross-culturally. A topic that has attracted much attention across disciplines is the increased prevalence of somatic complaints amongst South Asians, which have often been labeled ‘idioms’ of emotional distress [39, 65–68]. Somatic complaints occur across all cultural groups, although there are marked differences in prevalence and features. Kirmayer and Young [69] caution against the belief that excess somatization in non-Western cultures represents an apparent ‘primitiveness’ or inability to express psychological distress. Psychological and somatic symptoms may be just as valid in the expression of distress, and the clinical significance of different symptoms remains unclear. For some cultural groups, expressing distress through physical complaints is likely to offer a socially acceptable route to disclosure. However, established scales such as the BDI-II and the Hospital Anxiety and Depression Scale [70] contain limited or no items related to the somatic features of psychological conditions [67]. This helpfully prevents the risk of items being endorsed due to an underlying medical reason but perhaps makes the scales less relevant for other cultural groups where somatic and psychological complaints co-exist or where somatic complaints dominate and obscure psychological expressions of distress [67]. Indeed, Beliappa [66] proposes that in non-Western cultures where the mind and body are not viewed as distinct entities or compartmentalized, the distinction between psychological and somatic complaints may be less meaningful. The accurate screening and diagnosis of depression must therefore take account of cultural variations in both the conceptualization and expression of distress.



### *Emic versus Etic Measures of Depression*

Culture undoubtedly influences the expression of psychological distress, and health professionals are aware of the challenges in providing care for patients from diverse cultural and ethnic backgrounds [71]. In light of the issues related to differing conceptualizations, symptom presentation, and the complexities involved in utilizing translation and interpretation, it may seem sensible to employ culture-specific measures of depression, developed within the Indian subcontinent. Such a stance is perhaps best understood by considering the distinction made in cross-cultural research between the emic and etic approaches [72].

The emic approach focuses on culturally bound constructs and culture-specific measurement of a phenomenon. An emic measure would seek to capture the unique features of distress, as experienced by a particular ethnic group. For example, using this approach, researchers have identified culture-bound somatic complaints, which act as idioms of distress. Krause [41] identified the ‘sinking heart’ in Punjabis in Bedford, UK, which most closely resembled the Western conceptualization of stress. Similarly, Sulaiman et al. [73] reported the term ‘broken body’ used by an Arab community sample in Dubai to describe depressive phenomenon. Exploration of culture-bound syndromes has also led to the development of a number of indigenous instruments for the measurement of psychological distress. For example, the Primary Care Psychiatric Questionnaire [74] was developed to measure non-psychotic features of distress in India. There are numerous other examples of screening instruments developed locally to meet the linguistic needs and capture the unique features of distress, as experienced by members of a given ethnic group [67, 75, 76].

The etic approach, on the other hand, seeks to identify features of distress that are culture-general [72, 77]. This approach assumes that the aetiology of distress is universal and emphasizes equivalence in the measurement of distress cross-culturally [78]. Such an approach is advanced by studies utilizing measures developed in the West, such as the BDI-II, with other ethnic groups.

At present, there is limited evidence to aid clinicians in making informed decisions about whether to employ an emic or etic approach to screen for distress in South Asian patients. Bhui et al. [79] describe a study in which the screening accuracy of the Amritsar Depression Inventory (ADI [80]), an instrument developed and validated in Punjab in India, and the General Health Questionnaire (GHQ-12 [81]) was compared against a clinical diagnostic interview for primary care attenders originating from Punjab in India. The study found that for Punjabis who had lived in the UK for over 30 years, the ADI was no better than chance at detecting depression symptoms, although the scale functioned as well as the GHQ-12 in English subjects. The GHQ-12 was more accurate overall in the detection of depression symptoms in English and Punjabi primary care attenders.

More recently, Stahl et al. [82] suggested that Western screening instruments such as the Centre for Epidemiological Studies Depression Scale (CES-D [83]) achieve sufficient sensitivity and specificity in identifying significant depressive symptoms in South Asian patients with diabetes in Singapore, although the results need to be interpreted with caution in light of the statistical power of the study. A review of depression screening instruments available in Urdu, on the other hand, concluded that there is insufficient evidence to advance the use of Western translated scales over measures developed in indigenous languages, primarily due to a lack of reporting on cross-cultural validity and criterion reliability [84].

Both emic (culture-specific) and etic (universal or culture-general) depression screening tools are currently employed across studies with both clinical and non-clinical groups of South Asians. However, many of the scales are employed without adequate testing of the validity of the scales in the population of interest, and indeed Bhui et al. [79] suggest that expressions of distress may vary between sub-groups of a broad ethnic group, especially

due to the process of acculturation, i.e. the process through which members of a minority group adopt the beliefs and behaviours of the majority. Depression screening and diagnosis needs to be mindful of the complexities highlighted above both in the reliance on translation and interpretation, and the use of emic and etic screening instruments. For emic screening instruments, there needs to be careful consideration on how to assess the diagnostic accuracy of scales. The use of emic measures assumes that the experience of depression is culture-specific and so it may not, for example, be appropriate to compare such instruments with Western diagnostic criteria, such as those of the DSM-IV, which assume that depression is a universal phenomenon, the subjective experience of which is ‘culture-general’.

## Conclusions

The consequences of the under-representation of South Asian patients in research into the experience, measurement, diagnosis and treatment of depression in ESRD are far-reaching, preventing benefits from being generalized across patient groups. Such practice also undermines the agenda of the UK National Health Service to reduce inequalities in health care provision. Depression screening and diagnostic schemes are limited by the assumption that depression, as defined by the Western biopsychiatric model, is a universal phenomenon, the subjective experience and expression of which is common across different cultural and ethnic groups. Renal health professionals need to be mindful of the issues outlined in this article when assessing a patient’s psychological well-being. Information from interpreters should be used in conjunction with discussion with the patient’s family and assessment from bilingual mental health professionals. Research into the thoughts and feelings of South Asian patients with ESRD, the evaluation of emic measures of psychological distress or the adaptation of etic scales is encouraged and should be based on sound evaluation of both the process of scale construction/translation and reporting on validity.

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