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## **Epidemiology of depression in diabetes: international and cross-cultural issues**

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## Abstract

This paper reviews the most up-to-date epidemiological evidence of the relationship between depression and diabetes, and considers the risk factors for the development of depression and the consequences of depression in diabetes with an emphasis on international and cross-cultural data. The difficulties that researchers face when epidemiological studies require assessment of psychological phenomena, such as depression, across different cultural settings are explored.

## Methods:

Relevant papers were sought on the epidemiology of diabetes and depression in people with diabetes by undertaking a literature search of electronic databases including MEDLINE, Psych-INFO, CINAHL and EMBASE. These papers were assessed by the authors and a narrative review of the relevant literature was composed.

## Results:

Systematic reviews of the prevalence of depression in people with diabetes have focused on studies conducted in English speaking countries and emerging data suggest that there may be international variations in prevalence and also in how symptoms of depression are reported. There appears to be a bi-directional relationship between depression and diabetes, with one influencing the other; however, research in this area is further complicated by the fact that potential risk factors for depression in people with diabetes often interact with each other and with other factors. Further research is needed to elucidate the causal mechanisms underlying these associations.

## Limitations:

Data from non-English speaking countries remain scarce and so it is difficult to come to any firm conclusions as to the international variation in prevalence rates of co-morbid diabetes and depression in these countries until further research has been conducted.

Conclusion:

It is important to take a culture-centered approach to our understanding of mental health and illness and has outlined some of the key issues related to the development of culturally sensitive depression screening tools. In order to come to any firm conclusions about the international variation in prevalence of co-morbid diabetes and depression, issues of culture and diversity must be taken into account prior to conducting international epidemiological studies.

Key words: epidemiology, prevalence, psychological consequences, cross-cultural studies, international variations.

## Introduction

The close relationship between depression and diabetes has long since been recognised; in 1675, Willis noted that diabetes often appeared among patients who had experienced 'significant life stress, sadness or long sorrow' (Willis, 1674-1675). However, it was not until the late 20<sup>th</sup> century that epidemiological studies started to discover the complexities of the interrelationship between these two conditions. To date, the majority of studies have been carried out in English speaking countries in the developed world, although research is now beginning to emerge from non-English speaking countries and from low and middle income countries. In this paper we review the epidemiological evidence of the depression and diabetes link, the risk factors for the development of depression and the consequences of depression in diabetes with an international and cross-cultural emphasis. Further, we explore the difficulties that researchers face when epidemiological studies require assessment of psychological phenomena such as depression across different cultural settings.

## *Methods*

Relevant papers were sought on the epidemiology of diabetes and depression by undertaking a literature search of electronic databases including Academic Search Premier, MEDLINE, Psych-INFO, CINAHL and EMBASE. Only articles and abstracts published in English were considered. Based on titles and abstracts, potentially relevant studies were identified and the full texts of these articles were examined for final determination of relevance. These articles were assessed by the authors and a narrative review of the relevant literature was composed.

### *International variations in prevalence of depression in diabetes*

It is now generally agreed that the prevalence of depression is increased in people with diabetes. Early meta-analytic evidence showed that the overall odds of depression was twice as high for people with diabetes compared to non-diabetic controls (Odds Ratio (OR) = 2.0, 95% CI 1.8 to 2.2) (Anderson et al., 2001). This meta-analysis included studies of both type 1 and type 2 diabetes and no significant differences in prevalence were found between these two types of diabetes. Although this meta-analysis is often cited to indicate that depression is highly prevalent in people with diabetes, the sample sizes were relatively small and only a minority of the studies ( $n= 20/48$ ) compared prevalence data with a non-diabetes control group, limiting the conclusions that can be drawn. In a more recent meta-analysis of 10 controlled studies focussing on type 2 diabetes only, a somewhat lower prevalence rate of depression was found in people with diabetes compared to controls (17.6% vs. 9.8%; OR = 1.59; 95% CI 1.5 to 1.7) (Ali, et al., 2006). Although no meta-analysis has specifically looked at depression in type 1 diabetes, a systematic review of 4 controlled studies reported that the prevalence of clinical depression was 12.0% for people with type 1 diabetes compared to 3.2% in people without diabetes (Barnard et al., 2006).

The studies included in these systematic reviews and meta-analyses were all conducted in the USA or in West-European countries. However, rates of depression can vary between the sub-populations in these countries; for example, depression is higher in African Americans with diabetes than in their counterparts of White Northern European ancestry (Gary et al., 2000; Thomas et al., 2003). Other studies have found even higher levels of co-morbid diabetes and depression in the US Latino population (Egede et al., 2003; Bell et al., 2005, Fisher et al., 2001, 2004;

Trief, 2006) and in Native Americans (Singh et al., 2004) although a more recent study among Pima Indians in Arizona found no significant differences in depressive symptoms between those with and without diabetes (Sahota et al., 2008). It is likely that differences in cultural and social dynamics along with social stressors shape the way illness and health are experienced in the general population. For example, a study examining explanatory models of depression showed that Spanish speaking American Latinos experienced depression as a serious condition linked to acculturation and the accumulation of social stressors (Cabassa, et al., 2007). Physical and anxiety symptoms were commonly used to describe depression, and were linked to emotional distress and reduced functioning in this low-income group (Cabassa et al., 2008). Interestingly, the relationship between depressive symptoms and physical functioning was stronger in Filipino Hawaiians than in native Hawaiians and Hawaiians from mixed ethnic ancestry or from Japanese descent (Keawe'aimoku et al., 2006). Cultural differences in the way ethnic groups express emotional distress may explain these differences (Ponce, 1980). Although these studies did not specifically focus on people with diabetes, it seems likely that these cultural and social dynamics also contribute to the experience of depression in that population.

Recently, there has also been an increase in studies examining the prevalence of depression in diabetes from countries in other parts of the world. Using a representative sample, a recent Brazilian study found an increased prevalence rate of co-morbid depression in older people (OR= 1.58; 95%CI 1.29 to 1.95) (Blay et al., 2011). When looking at the prevalence of diabetes in people with major depressive disorder, a large population-based study from Taiwan found a higher prevalence of diabetes among individuals with diagnosed depression compared to the general population (OR = 1.53, 95%CI 1.39-1.69) (Chien et al., 2011). In this study, the

increased prevalence of diabetes was especially prominent among people with depression in their thirties, suggesting that lifestyle factors among this age group may be involved.

Furthermore, in a survey carried out in 60 countries across the globe, Moussavi et al. (2007) found that the self-reported 1-year prevalence of depressive symptoms in diabetes was 9.3% compared to 3.2% in people without a co-morbid condition. The prevalence of depression in this study was even greater in people with arthritis (10.7%, 95% CI 9.1 to 12.3), angina (15.0%, 95% CI 12.9 to 17.2) and asthma (18.1%, 95% CI 15.9 to 20.3).

While levels of depression were lower in a study from Pakistan, the prevalence of depression was nearly 15% amongst those with diabetes compared to 5% amongst those without diabetes (Zahid et al., 2008); this three-fold increase of depression in diabetes was consistent with the findings reported by Moussavi et al. (2007). High rates of depression have also been observed in Australia in both individuals with type 1 and type 2 diabetes (Hislop et al., 2008, Goldney et al., 2004), Jordan (Al-Amer et al., 2011), Pakistan and Qatar (Bener et al., 2011).

In summary, there is now firm evidence from studies from around the world that the prevalence of depression is increased in people with type 1 and type 2 diabetes; however, levels of depression may vary between countries and between populations within countries and between the sexes.

#### *Prevalence of depression in undiagnosed diabetes*

In contrast to the increased prevalence rate of depression in people with known diabetes, studies have found that the risk of depression is not higher in people who



have diabetes but are unaware of having the condition. A recent meta-analysis (Nouwen et al., 2011) found that the prevalence of elevated depressive symptoms in people with undiagnosed diabetes did not differ significantly from those with normal glucose metabolism (OR 0.94; 95%CI 0.71 – 1.25) but was lower than the prevalence among those with diagnosed diabetes (OR 0.57; 95% CI 0.45–0.74). Results for people with impaired glucose metabolism mirrored those of people with undiagnosed diabetes. Further, these results could not be attributed to differences in blood glucose concentration between diagnosed and undiagnosed diabetes. In contrast, in a rural Bangladeshi population nearly one third (29% men, 30% women) of those with undiagnosed diabetes reported clinically significant levels of depression, compared with only 6% of men and 15% of women without diabetes (Asghar et al., 2007). Since Nouwen et al's meta-analysis, two further studies have reported the prevalence of depressive symptoms in undiagnosed diabetes. In a study from Finland, a higher prevalence of depressive symptoms was found in previously diagnosed diabetes but not in undiagnosed diabetes or in those with impaired glucose regulation in comparison to people with normal glucose metabolism (Mäntyselkä et al., 2011). In contrast, undiagnosed diabetes and impaired glucose tolerance was associated with a modestly increased higher prevalence of depressive symptoms in a large population-based study of more than 23,000 people in southern India (Poongothai et al., 2010). The age and gender adjusted ORs were 1.10 (95%CI 1.02 to 1.19) and 1.09 (95%CI 1.01 to 1.18), respectively, which are within the limits found in the Nouwen et al. (2011) meta-analysis.

Because both people with impaired glucose metabolism and undiagnosed diabetes have higher blood glucose concentration than people with normal glucose metabolism, the conclusions from these studies seem to indicate that

hyperglycaemia *per se* is not associated with an increased level of depressive symptoms. One explanation for this finding is that the psychological burden of knowing that one has diabetes, having to manage this chronic illness and to cope with its complications and any resulting functional impairment contributes to higher levels of depression. However, this does not exclude the possibility that biological factors account for the difference in the prevalence of depression between diagnosed and undiagnosed diabetes. For example, diabetes complications have been linked to the development of depression (Teodorczuk et al., 2010; Pouwer et al., 2003). Unfortunately differences in diabetes-related complications between people with undiagnosed diabetes and this with diagnosed diabetes were not taken into consideration in the above mentioned studies.

It is currently unclear how and when depression develops after the diagnosis of type 2 diabetes. In a study from Pakistan, the prevalence of depressive symptoms in people with newly diagnosed diabetes was found to be significantly higher four weeks after diagnosis of type 2 diabetes (Perveen et al., 2010), while a large prospective study from the USA found that the risk of depressive disorder increased in the two years after diagnosis of type 2 diabetes even in the absence of diabetes complications (O'Connor et al., 2009). On the other hand, a UK study found that the prevalence of depression was not significantly different from a normative sample in the first year after diagnosis, although a significant number of people had persistent depressive symptoms during that year (Skinner et al., 2010). Use of antidepressant medication was also increased temporarily during the first year after diagnosis of type 2 diabetes (Kivimäki et al., 2010). These studies indicate that during the period following the diagnosis of type 2 diabetes, important changes occur that are likely to be associated with the development of depression.

### *Risk factors for developing depression in people with diabetes*

Although epidemiological evidence remains limited, studies have identified a number of risk factors that are common for both diabetes and depression, including low birth weight and fetal under-nutrition (Thompson et al., 2001; Paile-Hyvärinen et al., 2007), obesity (Moreira et al., 2007) and difficulty with daily living and reduced autonomy (Bruce et al., 2006; Anstey et al., 2007, Pawaskar et al., 2007). Increased risk for depression in people with diabetes may also be attributed to lifestyle and health behaviours; for example, a recent longitudinal study from the Canary Islands showed that intake of trans-unsaturated fatty acids, but not of mono- or polyunsaturated fatty acids, was associated with increased levels of depression (Sánchez-Villegas et al., 2011). Depression risk factors that are specific to diabetes include co-morbidity of diabetes-related complications (de Groot et al., 2001), and in particular macrovascular disease (stroke, peripheral artery disease) (Bruce et al., 2006) and microvascular disease including retinopathy (Katon et al., 2009), neuropathy and nephropathy (van Steenberg-Weijnenburg et al., 2011), longer duration of diabetes (Padgett, 1993; Bruce et al., 2005), more demanding regimens (Surwit et al., 2005), low levels of daily activities (Wikblad et al., 1991; Pawaskar et al., 2007) and physical activity (Lysy et al., 2008), , nutrition e.g., low intake of omega-3 fatty acids (Fitten et al., 2008), and perceived burden of diabetes (Polonsky et al., 1995). The majority of these studies, however, were cross-sectional and studied factors associated with depressive symptoms rather than with a diagnosis of major depression. To date, only three studies have examined longitudinal and multivariable risk factors for major depressive disorder. In a sample of older adults, Bruce et al. (2006) found that multivariable, longitudinal predictors of depression (including major and minor depressive disorder) included diabetes diet, increased cholesterol and difficulty in daily living. In a 5-year long longitudinal study, Katon et

al. (2009) found that a previous history of major depressive disorder, the number of diabetes symptoms at baseline and having undergone cardiovascular procedures during the study period, significantly predicted major depressive disorder at the 5-year follow-up. In another study, Naranjo et al. (2011) examined demographic (age, gender, race, income), behavioural (diet and exercise adherence), biological (HbA<sub>1c</sub>, body mass index, number of co-morbidities, number of diabetes complications) and psychosocial factors (prior major depressive disorder, number of negative life events, negative affect at baseline) as possible predictors of major depressive disorder in a group of over 300 adults patients with type 2 diabetes during an 18-month period. Significant predictors of major depressive disorder were found in each of these categories with the exception of behaviour. However, when the significant predictors within these categories were entered in a combined model, only prior major depressive disorder and negative affect at baseline remained significant. The results of these longitudinal studies therefore confirm earlier observations (e.g., Lustman et al., 1997; Kovacs et al., 1997b, Peyrot and Rubin, 1999) that major depressive disorder is a recurrent or chronic condition in diabetes. It is important to note that research in this area is further complicated by the fact that potential risk factors for depression in people with diabetes often interact with each other and with other factors. For example, the relationship between duration of diabetes and depression may be confounded by the number of complications present.

### *Consequences of depression in people with diabetes*

Although depression is a co-morbid condition in many physical health problems, people with diabetes who are depressed report the greatest decrements in perceived health compared with those with any other chronic illness (Moussavi, et al., 2007). For people with diabetes, the reduction in quality of life is only one of the adverse

consequences of depression. Depression has also been associated with compromised self-care (Gonzales et al., 2008) and poor metabolic control (Lustman et al., 2000; Richardson et al., 2008), particularly in those taking three or more insulin injections per day (Surwit et al., 2005). In addition, the risk of dementia, already increased in people with diabetes, is further increased 2.7 fold when comorbid with depression (Katon et al., 2010; Katon et al., 2011).

It is therefore not surprising that depression is also associated with an increased number of diabetes-related complications (de Groot et al., 2001), health service utilisation and healthcare costs (Egede et al., 2002) and mortality (Katon, 2011; Ismail et al., 2007). Concerning the latter, people with diabetes and major and minor depression have a 2.3 and 1.67 fold increase in mortality respectively compared to those without depression (Katon et al., 2005). The increased mortality rates are not limited to people with diabetes and a clinical diagnosis of depression; significant depressive symptoms, as assessed by scores of  $\geq 16$  on the Centre for Epidemiologic Studies Depression Scale (CES-D) have also been associated with increased mortality rates in people with diabetes by 54% compared to CES-D scores of  $< 16$  (Zhang et al., 2005). For people without diabetes, no significant relationships were found between depressive symptoms and mortality.

Depression has been proposed to exert an *additive* effect in those with diabetes (Egede et al., 2005). A large scale study separated 10,025 participants into four groups according to whether they had depression or diabetes or not. During the eight years follow-up, mortality (by any cause) was highest in those with both depression and diabetes (Hazard Ratio (HR) = 2.50; 95% Confidence Interval (CI) 2.04 to 3.08), compared to those with neither condition. Interestingly, those with depression alone

(HR = 1.20; 95%CI 1.03 to 1.40), or diabetes alone (HR = 1.88; 95%CI 1.55 to 2.27), still showed lower mortality rates than those with both conditions. This suggests depression and diabetes may have an adverse synergistic effect leading to the higher mortality rate. This effect has also been observed cross-culturally, in an older, Mexican American population (Black et al., 2003).

While the effect of diabetes and depression upon mortality undoubtedly exists, it is important to disentangle the effect of depression from other behaviours and conditions associated with diabetes, such as diabetes self-management and diabetes complications. An Australian study of over 1,000 patients with type 2 diabetes found that depression was associated with increased risk of mortality. Furthermore, behavioural effects secondary to depression (e.g. lower levels of exercise, poorer management of medications such as lipid lowering therapy) also contributed to the prediction of mortality. However, after adjustment for baseline micro- and macro-vascular complications, depression was no longer a significant predictor (Bruce et al., 2005) suggesting that depression increases mortality by increasing diabetic complications, specifically, macro-vascular and micro-vascular disease. However, a recent study controlling for these demographic and clinical characteristics, health habits and disease control measures, found major depression, but not minor depression, was significantly linked to all-cause mortality (HR = 1.24; 95%CI 1.19 to 1.95), and non-cardiovascular/non-cancer mortality from causes such as infections and dementia (HR = 2.15; 95%CI 1.43 to 3.24), (Lin et al., 2009). Further research is clearly needed to elucidate the causal mechanisms underlying the depression and mortality association.

In summary, there is now strong evidence demonstrating the relationship between diabetes and depression, both in terms of the prevalence and also the risk factors for and consequences of these co-morbid conditions for both the individual and society. Although the vast majority of this research has been conducted in English speaking countries, there is now an emerging literature from non-English speaking countries and from the developing world. However, this brings with it a new set of challenges as most depression measures have been developed outside this arena and issues of culture and diversity in the reporting of and experience of depression symptoms still require addressing. It is to these concerns that we now turn.

#### *Using depression screening tools in a global context*

The previous sections have outlined some of the key international findings with regard to what is known about the prevalence of co-morbid diabetes and depression. There is evidence that depression is under-recognised and under-treated throughout the world, especially in primary care settings (Patel, 2001; Ballenger et al., 2001; Lecrubier, 2001). The World Health Organization multi-country study demonstrated that primary care physicians in their study centres detected only half of all cases of depression (Sartorius et al., 1996). Treatment-seeking for depressive symptoms is relatively rare in many non-western societies and among immigrant and ethnic minority groups in the west (Patel, 2001; Teja et al., 1971; Sue et al., 1994; Swartz et al., 1994).

Most of the published research in this field has been conducted in English-speaking countries or in the developed world, and much less is known about the epidemiology of depression in people with diabetes in low or middle income countries or in non-English speaking countries. However, an important issue that requires consideration

is whether or not the screening tools commonly used may be simply transferrable to other nations or cultures of the world or whether more culturally relevant tools are required.

Physician recognition of mental disorders is generally low in non-industrialised countries including South Asia (Patel et al., 1998), and improving recognition rates is a challenge because of the high patient loads, poor undergraduate training in these skills, and the stigma associated with mental illness and somatic presentations of mental disorders. There is some evidence that, even in industrialised countries such as the UK, general practitioners' consultations regarding mental health problems are influenced by patients' cultural beliefs and practitioners' perception (Helman, 1999; Bhui et al., 2002). A number of research studies argue that the 'Western' classifications of depression proposed by both ICD-10 and DSM-IV (American Psychiatric Association, 1994) might not be simply applicable to other cultures (Bhugra and Mastrogianni, 2004; Weiss et al., 1995; Ballenger et al., 2001; Kirmayer, 2001).

Accurate measurement of mental health illnesses is necessary not only for clinical and ethical reasons but also to enable comparisons between different cultures. Thus, defining concepts of depression in accordance with both a psychiatric framework and lay beliefs and taking into account social contexts and cultural perspectives that give meaning to everyday life should all be incorporated into psychiatric assessment and practice (Bhugra and Mastrogianni, 2004; Bhui, 1999).



Interest in culture as an important determinant in psychiatric research emerges at a time when there is huge demographic change in the ethnic composition of many Western countries. A culturally sensitive approach to healthcare is one that considers ethnic minorities' particular requirements within a health system. This approach emphasises providing minorities with the same sort of health service as mainstream society, but at the same time taking into account the cultural 'diversities' of the minority groups.

Measuring depression across cultures has always been a source of controversy, but research suggests there are ethnic and cultural variations in the presentation, and general practitioners' assessment and management of common mental health problems (Bhui and Bhugra, 2011; Hussain et al., 1997; Commander et al., 1997; Jacob et al., 1998). One major concern has been the use of screening tools that have been developed in English-speaking countries and subsequently utilised in non-English speaking countries (Roy et al., 2011).

Different researchers and practitioners advocate different methods for measuring psychological well-being in people from different ethnic or cultural groups, with two main anthropological approaches usually considered as conflicting; the first of these is the 'etic' approach, which focuses on the perceptions of professionals and assumes that mental health problems can be conceptualized by a bio-medically driven psychiatry. Hence any screening tool is considered automatically valid in any setting. This approach underpins the bulk of epidemiological research worldwide, particularly in western industrialised countries. In contrast, an 'emic' approach is one which is based on acknowledging the perceptions of the local community. When it comes to the question of using depression screening

instruments, 'emic' instruments are those developed in the culture in which they are to be used, and 'etic' ones are developed in one culture but used without reservation in other cultures (Okpaku, 1998). Most research still uses 'etic' instruments, despite the criticism that one cannot apply diagnostic or other research instruments developed in one culture to people living in another (Kleinman, 1988). In order to overcome the limitations of both these approaches, researchers have recently attempted to combine quantitative research with an approach which uses local narratives and explanatory models of mental health problems (Aidoo and Harpham, 2001; Weiss et al., 1995; Lloyd et al., 1996). The use of two or more different data collection methods (often termed 'triangulation'), where the findings are compared and integrated, has indeed proved useful in gaining insights into the research question from different perspectives.

[Box One about here]

### *Cultural meanings of depression*

Evidence suggests that the prevalence of depressive disorders may differ between countries and within countries, and across various ethnicities (Ruiz, 2001).

Moreover, depression in individuals is known to be influenced by social and cultural factors, hence it is likely that the occurrence of depression will vary among and within societies (Miyaoaka et al., 1997). In a recent empirical research study examining ethnic differences in depression in people with diabetes in the UK, South Asians reported lower levels of diagnosed depressive disorder compared with their white European counterparts (Ali et al., 2006). However, the authors noted that this may have resulted from differences in either the presentation of symptoms or a lack of cultural appropriateness of western methods of identifying depression. Similarly, in a survey of Punjabi and English general practice attendees in London, Bhui et al.

(2001) reported that the Punjabis were not rated as having more depression than the English participants, but they did have more depressive ideas. Although the association between depression and diabetes has been found consistently, the trans-cultural validity of these findings remains to be shown. In our own work we have found that it was common for South Asians with diabetes from both the Bangladeshi and Pakistani communities living in the UK to express depressive symptomatology in somatic (physical pain) rather than cognitive terms (Lloyd et al., 2011). During focus group sessions with Sylheti speakers in the UK and in the one-to-one interviews with Sylheti speakers in Bangladesh, participants were asked whether they recognised terms such as ‘depressed’, ‘cheerful’ and ‘feeling down’, and were asked to consider the meaning these terms had in their culture. Participants were clear that they understood what feeling ‘depressed’ or ‘feeling low’ meant to them. However, a range of local terms and descriptions were used to express their understanding of the concept of depression, which are summarized in table 1. The participants also described a wide range of physical, emotional and social problems as manifestations of depression.

[Table One about here]

Our research findings support previous research in other cultural groups. For example research in Arabic populations has shown that patients use a variety of somatic descriptions to express the meanings of depression (Hamdi et al., 1997) and often associate depression with aches, pains and weakness (Sulaiman et al., 2001). The actual term ‘depression’ itself is often absent from the languages of many cultures or rarely used (Salim, 2010; Hamdi et al., 1997; Manson, 1995), or it is construed differently (Lloyd et al., 2011; Bhugra and Mastrogianni, 2004; Lee, 1998).

In those individuals with diabetes who took part in our research, depression was frequently described in terms of somatic symptoms, some of which may be confounded by the symptoms of diabetes (for example, appetite changes, poor concentration, fatigue). Furthermore, many of our research participants demonstrated a sense of the all-pervading nature of symptoms of depression which overlapped and impacted on how they experienced their diabetes and its management (Lloyd et al., 2011). This has implications for both the identification *and* the appropriate treatment of depression as well as the provision of support for diabetes self-management.

Variations in symptoms and ways to describe depressive symptomatology can be seen as culturally influenced (Lloyd et al., 2011). Earlier (western) studies suggested that somatisation (the process by which psychological distress is 'converted' to somatic symptoms) was the cultural equivalent of depression, typically occurring in non-Western cultures (Patel, 2001). However, there is now growing evidence from studies in primary and general health care settings that somatic symptoms are common presenting features of depression throughout the world regardless of cultural background (Lloyd et al., 2011; Chowdhury, 1979; Farooq et al., 1995; Katon and Walker, 1998; Simon et al., 1999; Salim, 2010; Desjarlais et al., 1995). Reporting somatic symptoms depends on how somatisation is defined cross-culturally (Simon et al., 1999; Lynch and Medin, 2006; Salim, 2010). Some symptoms may be universally recognised and some culturally distinct, but all are meaningful within particular cultural contexts. Therefore, it is important to understand the local term(s) and the culturally distinctive understandings of the causes of depression, the effects of particular health problems, and help-seeking in

the community if identification and treatment of co-morbid diabetes and depression is to be improved.

Indeed, patients and their families may have their own ideas about the illness as opposed to clinicians' views. For example, research among South Asian populations has shown that patients with depression usually link their depressive symptoms to different causes, for example any upsetting conditions, accidents or daily occurrence of events, unfavourable living conditions, financial problems or physical illness, and therefore consider it as a natural occurrence (Bhui et al., 2001; Chodhury, 1979; Farooq et al., 1995; Salim, 2010). In our own research, individuals with diabetes reported that problems with managing their diabetes led to feelings of low mood and hopelessness (Lloyd et al., 2011). As the meaning and understanding of the causes of depression change as a result of cultural and geographical influence it is crucial to consider these issues while developing culturally sensitive depression measurement instruments.

#### *Translation dilemmas in cross-cultural work in diabetes and depression*

Notwithstanding the above concerns, there remains a need to identify and offer treatment to those with depression or other debilitating mental illnesses, particularly when other physical illnesses such as diabetes co-exist. Of primary importance, in order to meet this aim, the concepts of depression and mental health and well-being need translating across cultures in order to develop culturally appropriate measurement tools, diagnosis and services for depression. At the outset, rigorous translation procedures should be in place using forward and backward translation techniques. In our own research these methods have been used, with any discrepancies in the back translation discussed and a final

version agreed between the two translators and the researchers, a process which we consider as an essential step to achieve cultural accuracy and/or equivalency.

In addition, the way information is collected requires consideration. Whilst translations may be viewed as technically accurate, and also culturally sensitive, the content of the questionnaires and the actual mode of data collection may still be seen as inappropriate by both those collecting the data as well as those providing the data. Self-rated instruments are not always appropriate in populations where there is a high prevalence of illiteracy or where the main language does not have an agreed written form and is only spoken (Williams et al., 1999). Our previous research has demonstrated the potential of a range of different modes of data collection in these ethnic groups, including audio versions of questionnaires, so that individuals may still participate in research and respond to survey tools, regardless of literacy level and in the knowledge that their responses are not overheard by others but are recorded privately and confidentially. (Lloyd et al., 2008a; Lloyd et al., 2008b; Roy and Lloyd, 2008). Using alternative modes of data collection facilitates inclusivity and helps ensure that anyone can participate fully in both research and clinical practice.

Through our own experiences in the translation and interpretation of data we have learned that communication across languages involves more than a literal transfer of information, because the participants, interpreter and researchers are all involved in discussing concepts, ideas, positions which are all important parts of the negotiation process of getting to grips with 'cultural meaning' and 'cultural differences'. During translation and interpretation, researchers have to make decisions about the cultural meaning which language carries, and spend a lot of time trying to evaluate the degree to which different worlds inhabit the same meaning. In a similar way to a

researcher, interpreters have to position themselves actively in the process and are accountable to the way they represent the informants and their culture and languages. Working with multilingual researchers fluent in the languages of our informants has been an added advantage of our studies and has helped us to more fully understand the complex relationship between culture and the experience of physical and mental health and illness.

### Limitations

As data from non-English speaking countries are scarce it is difficult to obtain a clear picture of any international variations in the prevalence of or risk factors for co-morbid diabetes and depression. A further challenge is the lack of information of the cultural applicability of depression screening tools, making between country comparisons problematic.

### Conclusions

There is strong evidence (at least in English-speaking countries) of an increased risk of depression in people with diabetes as well as increased risk of developing diabetes in people with depression. The past two decades have seen a number of screening instruments being designed in developed countries, many of which have been adopted by international investigators for epidemiological investigations. The cultural applicability of these instruments, however, has yet to be established.

The experience of depression is recognisable across different cultures, although researchers agree that clinical presentation may vary significantly and that mobility, migration and globalisation are likely to influence both idioms of distress and pathways to mental health care (Bhugra and Mastrogianni, 2004). As somatic

symptoms are a prominent feature of depression, existing measures of depressive symptomatology may not be appropriate for certain language groups and it is important to adapt these according to cultural reality of the study settings and participants in order to identify those in need of psychological care and treatment.

*CE Lloyd and T Roy designed the paper and wrote the outline. A Nouwen and A Chauhan wrote the first half of the paper; CE Lloyd and T Roy wrote the second half. CE Lloyd and A Nouwen edited the manuscript and all authors have approved the final manuscript.*

**There are no conflicts of interest for the authors of this paper.**



**BOX ONE:**

**An 'emic' approach to measuring symptoms of depression:**

- **Importing tools from other countries not appropriate**
- **Use concepts and terms that are meaningful within a specific culture**
- **Develop new tools which include culturally specific domains**

**An 'etic' approach to measuring symptoms of depression:**

- **Existing tools are translated and adapted**
- **Translation aims to achieve an accurate meaning rather than exact linguistic precision**
- **Further psychometric assessment is required**

**Table 1: Local terms for depression in Sylheti speakers in the UK and**

**Bangladesh**

**UK study:**

**Sylheti speakers**

*Duschinta* (worry)

*Mon bejar* (bad mood)

*Mon mora* (sadness)

*Mon bala nay* (not in good mood)

*Tension* (anxiety)

*Dorod* (paid)

*Shorir Durbol* (tiredness)

*Matha var* (weight on my head)

*Buk var* (weight on the heart)

*Shanti nai* (joylessness)

Mental case

Off mood

**Bangladesh study:**

**Sylheti speakers**

*Duschinta* (worry)

*Chinta rog* (worry illness)

*Mon bejar* (bad mood)

*Mon mora* (sadness)

*Mathaye tension* (tension on my head)

*Dorod* (pain)

*Matha var* (weight on my head)

*Buk var* (weight on my heart)

*Shanti nai* (joylessness)

Mental

*Manoshik rog* (mental disorder)

**Bangladesh study:**

**Sylheti speakers**

*Duschinta* (worry)

*Chinta rog* (worry illness)

*Mon kharap* (bad mood)

*Mon var* (pressure on the mind)

*Tension* (anxiety)

*Tension rog* (anxiety illness)

*Durbolota* (weakness/tiredness)

*Beytha* (pain)

*Matha var* (weight on the head)

*Matha nosto* (going mad)

*Orthonoitik chap* (financial tension)

*Mathaye tension* (tension on the head)

*Buk dhorfor* (palpitation)

*Buk var* (weight on the chest)

*Hai hutash* (grievances)

*Manoshik chap* (mental pressure)

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