

# Double the trouble – the challenges around managing Diabetes and End Stage Renal Disease

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The prevalence of diabetes mellitus (DM) is very high worldwide. According to the World Health Organization in 2013 the worldwide prevalence of DM was in excess of 300 million (World Health Organization, 2013).

Diabetic nephropathy is a major vascular complication of DM

occurring in 20-40% of DM patients worldwide (American Diabetes Association, 2013; Hallan et al., 2006). If DM is not treated early and adequately, many diabetic patients may reach end-stage renal disease (ESRD) secondary to advanced irreversible diabetic nephropathy. The number of patients who have diabetes and ESRD and are being admitted to renal replacement treatments (RRT) is increasing dramatically, to the point that within many countries in the past few years, diabetes has or will soon become the most frequent single cause of ESRD (United States Renal Data System, 2013; Singapore Renal Registry, 2013). Although diabetes patients with ESRD are usually considered for renal transplantation and have been shown to do very well following a combined kidney pancreas transplant, high comorbidity may limit their possibilities for transplants and consign most patients onto dialysis.

Diabetic ESRD patients represent the segment most at risk for poor clinical outcomes. Although the prognosis of patients who have diabetes and are receiving RRT has greatly improved, survival and rehabilitation rates continue to be significantly worse than those of nondiabetic patients, mainly because of

pre-existing severely compromised cardiovascular conditions. More than 50% of diabetic dialysis patients die within 2 years of commencing dialysis (Broumand, 2007; United States Renal Data System, 2009). The main reason for such a high mortality rate is that the cardiovascular conditions of patients with diabetes are already severely impaired when they start RRT / dialysis, as demonstrated by the high prevalence of coronary heart disease, stroke, peripheral occlusive disease, and amputations (Eggers, Gohdes, & Pugh, 1999; Schömig, Ritz, Standl, & Allenberg, 2000; Stack & Bloembergen, 2001). Patients with diabetic nephropathy have the largest number of co-morbid conditions within the ESRD population (Lok, Oliver, Rothwell, & Hux, 2004). These conditions are mainly vascular in nature. More often than not patients with diabetic nephropathy organ damage is not limited to the kidney but also involves other organs resulting in retinopathy, neuropathy and cardiovascular complications.

ESRD and diabetes negatively affect not only life expectancy but also health-related quality of life (HRQoL) (Rubin & Peyrot, 1999) and thus patients with diabetes on haemodialysis tend to have very low HRQoL. Data from the Dialysis Outcomes and Practice Patterns Study (DOPPS - an international database to document dialysis practices and outcomes across over 20 countries) indicated that low levels of physical function or low self-rated physical HRQoL are predictive of future risk of death in patients with diabetes on haemodialysis (Hayashino et al., 2009).

Overall, the coexistence of diabetes, and ESRD leads to synergistic adverse effects: mortality is higher mainly due to cardiovascular complications, quality of life is worse and the burden on healthcare services is increased (McCullough, Bakris, Owen Jr,

Klassen, & Califf, 2004; Tong & Stevenson, 2007).

Despite the growth of this population, few studies have explored patient outcomes in multi-morbid patients in general (Bayliss, Steiner, Fernald, Crane, & Main, 2003; Mishra, Gioia, Childress, Barnet, & Webster, 2011) and in this diabetic ESRD group in particular (Williams et al., 2005; Williams, Manias, & Walker, 2008). Past work has focused on either ESRD or diabetes and documented substantial rates on non-adherence and emotional distress (Evans et al., 1999; Ruggiero et al., 1997). Evidence on how patients integrate and apply treatment recommendations for both diabetes and ESRD and patterns of adherence for the combined diabetic and renal regimes is still largely lacking.

Coexisting diabetes and ESRD place significant and rather complex self-demands on patients. Dialysis regimens are understandably significant sources of stress as they entail intrusive and time-consuming treatment schedules, dependency on others, reliance on technology for survival, unpleasant side-effects and complications. The treatment for DM ESRD involves a complex and demanding behavioural regimen above and beyond dialysis therapy. This includes continual nutritional management (e.g. restriction of dietary intake of phosphate and potassium-rich foods, and reduced salt and fluid intake), blood glucose control, foot care, multiple medications to facilitate management of blood pressure, anemia, and other problems related to extrarenal comorbidity, and recommendations related to exercise. The competing treatment demands of the two conditions can potentially result in poor management and misregulation as when treatment demands for one condition conflict with or impede management of the other, or when patients prioritize one condition over another (Bower et al., 2012; Morris, Sanders, Kennedy, & Rogers, 2011). A case in point is diet. A diabetic diet entails consumption of a healthy and balanced diet, which is very much in line with general guidelines about healthy eating. On the other hand, the renal diet is more complicated and restrictive, including avoidance of certain fruits and

vegetables high in potassium and restriction of fluid intake. Controlling fluid intake may be particularly challenging for diabetes patients who often experience excessive thirst as a result of their diabetes (Davenport & Willicombe, 2009; Sung et al., 2006).

Reconciling these complex and to some extent incompatible recommendations can be a real challenge for patients and caregivers alike. Ongoing support and tailored nutritional advice hence may be needed to facilitate readjustment of dietary behaviours once diabetes patients get established on renal replacement therapy.

There are several issues to take into consideration – motivation and ability may be lowered. The cognitive impairments of ESRD and diabetes (Griva et al., 2004; Luchsinger et al., 2007) may for instance, compromise patients' ability to acquire, understand, and retain the new dietary information. Furthermore, DM ESRD patients are diagnosed in late adulthood when health behaviours are firmly established and thereby harder to change. Another important consideration is that DM patients on dialysis are by definition a select group of patients with 'poor' record with regards to adherence and self-management. These are patients who have a history of poor self-management decisions, self-care behaviours and metabolic control given the development of diabetic nephropathy and need for dialysis. Low morale or hopelessness may be experienced which can undermine patients' motivation and confidence in effecting control and managing their conditions. Such feelings may further exacerbate the emotional consequences for multimorbidity and further increase the risk for mental health disorders (Barnett et al., 2012).

Depression is a common disorder, which is often co-morbid with long-term conditions such as ESRD and diabetes (Anderson, Freedland, Clouse, & Lustman, 2001; Kimmel, 2002; Kimmel & Peterson, 2005). The coexistence of depression, diabetes and ESRD may lead to underregulation of conditions (i.e. where depression lowers patient self-efficacy to

undertake self-management) or misregulation (i.e. where improvements in depression lead to changes in diet which in turn have a negative effect on disease management) (Piette, Richardson, & Valenstein, 2004).

To sum up, the coexistence of diabetes and ESRD, as well as multimorbidity in general presents both a challenge and opportunity for clinicians and researchers alike.

Until now the focus in both research and practice was on studying or managing single diseases. There is a need to bolster a patient-centered instead of the current single disease-focused approach, to broaden the focus on spectrum of multimorbidity and prevent fragmentation in the management by various specialists. This is the case for Health Psychology research work and psychological interventions (Smith, Soubhi, Fortin, Hudon, & O'Dowd, 2012). First, the study of large patient samples is a prerequisite to understand complex connections and interrelated impact of multiple chronic diseases such as ESRD and diabetes and identify the needs and outcomes more pertinent for these patients. Intervention programmes should ideally be tailored to these needs and move beyond the management of poly-pharmacy towards integration of the important lifestyle aspects of treatment for the coexisting conditions (Banning, 2009; Mishra et al., 2011; Williams, Manias, & Walker, 2009).

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