The amplified burden: understanding and addressing diabetes distress in transplant recipients

Care for patients in the post-transplant period often centres on graft function, optimising immunosuppression, preventing infection and forestalling long-term complications. For transplant recipients with diabetes – whether pre-existing or post-transplant – the need for daily self-management adds another layer of complexity, compounding the many competing medical, emotional and social adjustment demands and priorities.

Diabetes distress is a common consequence of living with diabetes, affecting around one in four individuals with type 1 diabetes and one in five insulin-treated people with type 2 diabetes. It is associated with suboptimal self-management, elevated HbA_{1c} levels and impaired quality of life (Dennick et al, 2015; Hendrieckx et al, 2020). This distress reflects the emotional burden of relentless self-management, fear of complications and frustration with constant glycaemic variability (Fisher et al, 2014).

Although well described in general diabetes populations, diabetes distress may be even more pronounced among transplant recipients. Alongside diabetes, they face additional challenges, such as immunosuppression, complex treatment regimens, unstable health status and psychosocial challenges.

Transplant diabetes nurses often encounter individuals who, despite understanding the risks, disengage from their diabetes care. The following encounters illustrate this challenge:

Case 1: A 28-year-old woman, who had previously stopped insulin therapy after a simultaneous pancreas and kidney (SPK) transplant, experienced pancreas graft failure resulting in the recurrence of diabetes. She declined the use continuous glucose monitoring (CGM) devices, citing a desire to dress freely without attachments and feeling overwhelmed by having "too many things going on." Despite unstable glycaemia, she disengaged from monitoring and insulin administration.

Case 2: A transplant recipient with type 2 diabetes, who was experiencing erratic blood glucose levels, stopped taking insulin and discontinued self-monitoring for three weeks as they felt frustrated and overwhelmed.

These narratives reflect common themes of diabetes distress:
- Feeling overwhelmed by the demands of living with diabetes.
- Feeling restricted by the condition or the devices used to manage it.
- A sense of anger, guilt or discouragement when treatment targets are not met.
- Device fatigue.
- Omitting insulin administration and not monitoring glucose levels.
- Sensing a loss of control.
- Disengaging from medical appointments and self-management.

(Hendrieckx et al, 2020)

Transplant clinicians may misinterpret patient behaviour as "non-adherence" when, in reality, many individuals are simply overwhelmed. Rather than being simply "non-compliant", many are experiencing diabetes distress driven by stressors such as anxiety about potential graft failure, medication burden, body image concerns and financial strain. Such factors can intensify overall distress and result in diabetes burnout, a state of physical and emotional exhaustion in which people feel detached from their care and powerless over their condition (Fisher et al, 2019). In the cases above, signs included disengagement from self-care, skipping medications and missing appointments.

This article asserts that the unique psychosocial and physiological context of transplant care can significantly amplify this distress, and provides a guide for its management.

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> ***"For transplant recipients, diabetes distress is not a minor complaint but a serious amplifier of disease burden, threatening both metabolic control and graft survival."***

Why is diabetes distress amplified in transplant patients?

Transplant recipients contend with a host of stressors that can converge to exacerbate the normal burdens of diabetes.

- **The "second disease" burden**: Post-transplant diabetes can be viewed as a second chronic disease after primary organ failure. Individuals may have hoped that their transplant would resolve their health problems, only to find that diabetes management remains a demanding, lifelong task. This can lead to profound frustration and disappointment.
- **Complexity of regimens:** Post-transplant care involves a complex regimen of immunosuppressants, anti-infective drugs and monitoring for rejection. The addition of intricate diabetes tasks, such as carbohydrate counting, insulin dose adjustment and device management, can be overwhelming, creating what is known as "regimen distress" (Polonsky et al, 2005).
- **Body image and autonomy:** Transplant recipients have already undergone a major bodily invasion. Attaching a CGM or insulin pump device can feel like a further violation of bodily autonomy and be a visible reminder of their illness.
- **Iatrogenic challenges:** Immunosuppressants such as corticosteroids and tacrolimus induce insulin resistance and hyperglycaemia, making glycaemic control very challenging. This can leave people with feelings of failure and powerlessness, as their efforts are undermined by essential medications (Hessler et al, 2013).
- **Fear of complications and graft failure:** Recipients know that poor glycaemic control can threaten the transplanted organ. This can cause significant distress, creating a vicious cycle in which anxiety about complications leads to avoidance of management.

A framework for nursing intervention: the 7 As model

The 7 As model is a dynamic seven-step process that provides a structure for healthcare professionals to support people with diabetes facing emotional challenges (Hendrieckx et al, 2020: Chapter 3). It is used in clinical practice as part of a person-centred approach and can be applied in the transplant setting.

Phase 1: How can I identify diabetes distress?

- Be **AWARE:** Look for signs beyond glycaemic control. These include missed appointments, passive or aggressive demeanour during consultations, and disengagement from self-care (e.g. stopping insulin). Remember, even patients with optimal control may experience severe distress if their efforts are unsustainable.
- **ASK:** Normalise the conversation. Use open-ended questions such as, "What is the most difficult part of managing your diabetes alongside your transplant care?" or "Many people find the constant demands after a transplant overwhelming; how has it been for you?"
- **ASSESS:** Use validated questionnaires like the Problem Areas in Diabetes (PAID) scale or the Diabetes Distress Scale (DDS). A PAID score ≥40 or a DDS mean score ≥3.0 indicates severe distress. High-scoring items provide a direct roadmap for conversation (Fisher et al, 2012).

Phase 2: How can I support the person?

- **ADVISE:** Explain diabetes distress and normalise their feelings. Acknowledge the demanding task of managing both transplant and diabetes. Crucially, reframe the narrative away from self-blame (e.g. "I am a failure") by explaining that diabetes outcomes are not a reflection of their character or effort.
- **ASSIST or ASSIGN:**
  - **ASSIST:** Collaborate on an achievable action plan. For an individual overwhelmed by devices, could a structured finger-prick schedule be a temporary, acceptable compromise? For someone fearing hypoglycaemia, could simplifying their insulin regimen or setting less strict targets provide relief? The concept of a "safe break from diabetes", such as agreeing to reduce monitoring frequency for a short period, can be a powerful tool to prevent burnout.
  - **ASSIGN:** Know when to refer. Given the complexity, a multidisciplinary approach is essential. Refer to a diabetes educator for regimen simplification, a dietitian for meal-planning support or a mental health

professional (preferably with understanding of chronic illness) for underlying anxiety or depression.

- **ARRANGE:** Schedule more frequent, shorter follow-ups. Use telephone or video consultations to reduce the burden of travel. Continuity of care and a trusting relationship with the nurse are critical for monitoring distress over time and preventing relapses.

Conclusion

For transplant recipients, diabetes distress is not a minor complaint but a serious amplifier of disease burden, threatening both metabolic control and graft survival. By moving beyond a purely biomedical model and integrating systematic assessment for diabetes distress into our routine practice, we can provide the compassionate, person-centred care needed. Recognising signs, initiating dialogue and using a structured framework enables us to support patients as individuals facing significant emotional and physical challenges – not merely as transplant recipients with diabetes. ■

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