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Navigating the emotional labyrinth: psychological challenges of living with type 1 diabetes and chronic kidney disease

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1. Introduction

Overview of Type 1 Diabetes (T1D)

Type 1 diabetes (T1D) is a chronic autoimmune condition where the body's immune system mistakenly targets and destroys the insulin-producing beta cells in the pancreas. Insulin is a hormone crucial for regulating blood glucose levels and allowing glucose to enter the body's cells to produce energy. Without sufficient insulin, blood glucose levels rise uncontrollably, leading to hyperglycemia with its acute complications, such as diabetic ketoacidosis (DKA), and chronic consequences, damaging blood vessels, nerves, and organs over time. The administration of exogenous insulin only partially mimics the intricate mechanisms of endogenous insulin secretion, putting the patients at risk of another acute, potentially life threatening, and quality-of-life reducing complication – hypoglycemia.

T1D is typically diagnosed in childhood or adolescence, though it can occur at any age. Unlike type 2 diabetes, which is often associated with lifestyle factors, T1D develops primarily due to a genetic predisposition combined with environmental triggers, such as viral infections. It accounts for about 5-10 % of all diabetes cases worldwide.

Managing T1D is a lifelong commitment requiring frequent blood glucose monitoring through multiple daily fingerstick tests or continuous glucose monitors (CGMs); insulin therapy via multiple daily injections or insulin pumps, dietary management: careful monitoring of carbohydrates and meal timing; physical activity adjustments: balancing exercise with insulin doses and meals and constant vigilance for hypoglycemia and hyperglycemia symptoms to prevent emergencies like DKA or severe hypoglycemia-induced unconsciousness.

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The prolonged exposition to hyperglycemia puts an individual with T1D at risk of developing complications that encompass microvascular damage: diabetic retinopathy, neuropathy and nephropathy, and macrovascular damage including atherosclerosis and cardiovascular diseases (ischemic heart disease, stroke and peripheral artery disease). Despite innovations in the treatment of T1D, the prevalence of diabetes complications is still high, with diabetic nephropathy causing chronic kidney disease (CKD) affecting up to 50 % of people living with diabetes [Selby 2020].

While advancements in medical technology, such as hybrid closed-loop insulin pumps and CGMs, have improved outcomes and quality of life, the emotional and psychological burden remains significant. The constant need for disease management creates mental exhaustion, anxiety, and emotional strain for patients [Holt 2021].

Overview of CKD

CKD is characterized by the presence of kidney damage or decrease of an estimated glomerular filtration rate (eGFR) of less than 60 mL/min/1.73 m², persisting for at least three months [3]. The gradual loss of kidney function over time in CKD impairs the kidneys' ability to filter waste products, regulate electrolytes, and maintain fluid balance. The CKD classification relies on the underlying cause, eGFR, and albuminuria level. The most common causes of CKD include diabetes, hypertension and obesity. Glomerulonephritis with the inflammation of glomeruli and genetic disorders, such as polycystic kidney disease, comprise rare etiologies of CKD. The prevalence of CKD is estimated to be around 10 % to 14 %, but given its asymptomatic nature in initial and moderate stages, the estimation of its true prevalence is challenging. Symptoms of CKD become evident in irreversible stages, as the disease nears its terminal phase [KDIGO 2024].

The symptoms of advanced CKD include fatigue and weakness, swelling in hands, feet, or ankles (edema), shortness of breath, nausea and vomiting, decreased appetite, itchy skin and muscle cramps. Managing CKD requires a multifaceted approach, including dietary restrictions: low sodium, potassium, phosphorus, and protein intake, medication management to control blood pressure and edema, iron supplementation, and the compensation of acidosis and electrolyte imbalances.

Despite the introduction of treatment and preventive measures, patients with CKD develop complications, such as anemia, secondary hyperparathyroidism, CKD mineral bone disorder, hyperkaliemia and have a significantly increased cardiovascular risk. In end-stage CKD patients require

dialysis or kidney transplantation for survival [KDIGO 2024].

The emotional and psychological toll of CKD is substantial, as patients face not only physical symptoms but also uncertainty about disease progression, financial burdens, and changes in lifestyle and independence [Ahola 2021].

The Intersection of T1D and CKD

When T1D and CKD coexist, their interplay creates a complex medical and psychological scenario. CKD is one of the most serious long-term complications of diabetes, with diabetic nephropathy being the leading cause of kidney failure worldwide. CKD is also a common complication in people with T1D, affecting 30 % to 40 % of all individuals [de Boer 2022, Heerspink 2023]. A study by Rossing et al. indicated that the prevalence of CKD in T1D was 21.5 %, corresponding to 258196 people in the U.S. between 2015 and 2017 [Rossing 2024]. Another study by Eliasson et al. showed that in the Swedish National Diabetes Register of people with T1D, the prevalence of CKD was 22.8 % [Eliasson 2022]. The prevalence of CKD in this population is higher in older age groups, however, as reported by Rivetti at al., children with T1D also bear an increased risk of developing CKD [Rivetti 2023]. This can be attributed to acute kidney injury (AKI) in childhood and long-term poor glycemic control [KDIGO 2024]. To assure timely diagnosis, routine annual screening for CKD is recommended [KDIGO 2024, Rivetti 2023].

The coexistence of T1D and CKD creates a vicious cycle of self-perpetuating increased risk of further kidney function deterioration and exponentially growing cardiovascular risk [de Boer 2022, Heerspink 2023]. CKD in T1D occurs typically due to the prolonged exposure to hyperglycemia, which triggers the accumulation of advanced glycation end-products (AGEs). AGEs and hyperglycemia induce oxidative stress and inflammation, with an increased production of reactive oxygen species (ROS) and proinflammatory and profibrotic factors damaging glomeruli and contributing to kidney scarring and fibrosis. Finally, the increased glomerular capillary pressure leads to hyperfiltration, occurring early in diabetes, which further damages the glomeruli [Selby 2020, KDIGO 2024].

CKD poses serious challenges to diabetes management and prevention of its further complications. The dietary recommendations are sometimes conflicting between T1D and CKD. Furthermore, as kidney function declines, insulin clearance decreases, leading to unpredictable blood glucose levels, increasing the risk of hypoglycemia. Progressive renal decline in T1D is associated with increased mortality risk, especially from cardiovascular causes [de Boer 2022, Eliasson 2022].

The medical management of both diseases requires a highly individualized care plan. Patients often need care from a multidisciplinary team, including endocrinologists, nephrologists, dietitians, mental health professionals, and social workers.

The emotional burden is equally profound. Individuals face fear of dialysis or kidney transplantation, frustration with treatment complexity, anxiety about hypoglycemic episodes, financial strain from dual disease management [Nyumura 2017].

The Importance of Psychological Support in Managing T1D and CKD

The dual diagnosis of T1D and CKD not only creates physical complications but also poses significant psychological challenges. The mental health burden often remains underrecognized and undertreated, despite clear evidence linking poor mental health outcomes to worsened physical health outcomes.

Key psychological challenges include chronic stress: from managing two demanding illnesses, depression and anxiety increased prevalence due to the uncertainty and burden of illness, emotional fatigue and burnout resulting from relentless disease management routines, cognitive impairment related to fluctuating glucose levels and CKD-related toxin buildup and social isolation from dietary restrictions, physical symptoms, and medical routines.

By addressing mental health it is critical to improve treatment adherence to insulin therapy, dialysis, and medications, enhance quality of life and emotional well-being, reduce hospital admissions and complications and empower to make informed health decisions.

Addressing the psychological aspects of these conditions requires a holistic approach that integrates mental health care into standard disease management protocols. This includes regular mental health screenings, access to counseling and therapy, peer support, and education programs tailored to help patients cope with the dual burden of diabetes and kidney disease.

This paper seeks to:

1. explore the emotional, cognitive, and behavioral impacts of living with both T1D and CKD
2. understand the challenges in relationships and social interactions faced by these individuals
3. highlight coping mechanisms, both adaptive and maladaptive, and their consequences
4. examine the role of healthcare systems and support networks in mitigating psychological distress
5. provide insights into therapeutic interventions that can enhance emotional resilience and overall well-being

By acknowledging and addressing these psychological aspects, we can create better care models that recognize the emotional, cognitive, and social dimensions of living with two intersecting chronic diseases.

2. Emotional Impact

Anxiety and Fear

Anxiety is a dominant psychological symptom among individuals managing T1D and CKD. The fear stems from numerous factors such as:

- hypoglycemia and hyperglycemia: Kidney impairment alters insulin metabolism, increasing the risk of unpredictable blood sugar fluctuations. Hypoglycemia, in particular, is a terrifying experience due to the risk of unconsciousness or seizures
- progression of kidney disease: Patients often fear advancing to end-stage kidney failure, requiring dialysis or transplantation. Hemodialysis in particular is a treatment dramatically disturbing life plans, professional careers and imposing significant financial burdens, as it is often incompatible with most full-time jobs, kidney transplant is considered a major surgery associated with both short-term risk and long-term immunosuppression complications
- uncertainty about future health: The chronic and unpredictable nature of both diseases creates a constant sense of vulnerability

Anxiety may manifest as restlessness and difficulty sleeping, avoidance of blood sugar or kidney function tests, over-monitoring or obsessive control of health metrics.

Depression

Depression is one of the most common mental health challenges for individuals with T1D and CKD. Research indicates that depression rates are significantly higher in individuals managing multiple chronic illnesses. Causes include constant exhaustion from both diseases, which can reuce interest in daily activities (chronic fatigue), grief at the loss independence, hobbies, and long-term health prospects, a sense of hopelessness, and being overwhelmed by the ongoing need for treatment and monitoring.

Depression may lead to poor treatment adherence, social withdrawal and isolation and suicidal ideation (in severe cases). Whether successful treatment of depression reduces the risk needs to be determined [Ahola 2021].

Emotional Exhaustion and Burnout

The perpetual cycle of managing medications, diets, dialysis schedules, and blood glucose monitoring can cause emotional burnout. Symptoms of burnout include loss of motivation to follow treatment plans, neglecting self-care routines, feeling emotionally numb or detached.

Burnout often worsens depression and anxiety, creating a vicious cycle of declining mental and physical health. The burden of diabetes-related CKD in China worsens and shows gender disparities and different age distribution [Pan 2022].

Guilt and Self-Blame

Many patients experience feelings of guilt or self-blame, especially if they perceive their health decline as a result of poor disease management. These feelings can lead to lower self-esteem, reluctance to seek help and increased psychological distress.

3. Cognitive Impact

Both T1D and CKD can independently affect cognitive function, but their combination intensifies these effects. Factors contributing to cognitive decline include: fluctuating blood glucose levels as both hyperglycemia and hypoglycemia can cause acute and chronic brain dysfunction; toxin buildup in advanced CKD, as waste products accumulate in the bloodstream, potentially affecting brain function and medication side effects as some medications for CKD and diabetes can have cognitive side effects, such as drowsiness or brain fog.

Symptoms of cognitive dysfunction include memory impairment (difficulty remembering medication schedules or medical advice), attention deficits (trouble focusing on tasks or following conversations and executive dysfunction) and struggling with planning, problem-solving, or decision-making. Cognitive difficulties can lead to frustration and embarrassment, increased dependence on caregivers and feelings of helplessness and vulnerability [Verhagen 2022, Shapiro 2023].

4. Behavioral Impact

Adhering to treatment plans is exceptionally challenging when managing two complex chronic illnesses. Barriers to adherence can be connected with complex medication schedules: multiple medications with specific timing requirements, conflicting dietary guidelines as the renal diet often clashes with diabetes dietary needs, leading to confusion and frustration and monitoring fatigue because frequent glucose checks, kidney function tests, and dialysis sessions can feel overwhelming. In response to psychological distress, some patients may skip medications or dialysis sessions, engage in emotional eating or substance abuse and avoid medical appointments The physical symptoms of fatigue, nausea, and weakness can prevent individuals from fulfilling work or social obligations, leading to reduced productivity, job loss or financial strain, social withdrawal.

5. Impact on Relationships

The management of both T1D and CKD often requires the active involvement of family members or caregivers. The interdependence that arises from this dual burden can lead to both positive and negative effects on family dynamics.

Patients may rely heavily on family members for medication management, dietary oversight, and transportation to medical appointments. Family members often become unofficial caregivers, which can create tension, particularly if they feel overwhelmed by the responsibility. Family members, particularly primary caregivers, may experience exhaustion, depression, and anxiety. The cost of managing both diseases can strain family budgets, adding another layer of tension. In families where the patient was previously a caregiver or primary provider, the shift in responsibilities can disrupt established family roles. Some families become closer and more supportive through shared challenges. Collaborative problem-solving and shared coping strategies can strengthen emotional bonds.

Romantic partnerships can be significantly impacted by the psychological and physical demands of managing T1D and CKD. Intimacy and physical connection may be affected by fatigue and physical symptoms such as constant tiredness, nausea, and other symptoms may reduce libido and physical intimacy.

Another aspect can be connected with body image issues: scars from insulin pumps, dialysis ports, or weight fluctuations can affect self-esteem and body confidence.

Partners may withdraw emotionally out of fear of being a burden or causing additional stress. Partners who lack a full understanding of the medical realities might misinterpret mood swings or fatigue as relationship issues.

In healthy relationships, partners often become active advocates for the patient's health. Open communication and shared decision-making about medical care can reduce misunderstandings. Chronic illnesses can significantly impact friendships and social engagement. Fear of judgment or misunderstanding may cause individuals to withdraw from social activities. Strict dietary restrictions or dialysis schedules can make it difficult to participate in social gatherings.

Connecting with others facing similar challenges can provide a sense of belonging and understanding. Online forums and local support groups can offer a safe space to share experiences and advice.

6. Coping Mechanisms

Effective coping mechanisms are essential for maintaining emotional resilience and managing the ongoing demands of T1D and CKD.

Psychotherapy and counseling

Cognitive-behavioral therapy (CBT) helps individuals manage negative thought patterns and develop problem-solving skills. Acceptance and commitment therapy (ACT) encourages acceptance of chronic illness while identifying values and goals to create a fulfilling life. Family therapy addresses relationship strain caused by chronic illness and promotes healthy communication.

Peer support groups

Talking to others who are navigating similar health challenges reduces feelings of isolation and fosters emotional connection. Support groups can also provide practical tips for managing both conditions.

Mindfulness and stress reduction techniques

Meditation and Yoga may help reduce stress, improve emotional regulation, and promote relaxation. Breathing exercises can help to manage moments of anxiety and emotional distress.

Building routine and structure

Consistent daily routines for medications, blood glucose checks, and meals can reduce decision fatigue and improve adherence.

Maladaptive Coping Mechanisms

When emotional distress becomes overwhelming, some individuals may resort to unhealthy coping strategies such as substance abuse, emotional eating manifested in using food to cope with stress, which can worsen both blood glucose control and kidney health and avoidance strategies like ignoring medical appointments, skipping dialysis sessions, or neglecting insulin therapy. Addressing maladaptive coping mechanisms often requires professional intervention and ongoing support from healthcare providers.

7. Identity and Self-Perception

Many individuals with T1D and CKD begin to define themselves through the lens of their illnesses. This „illness identity“ can affect self-esteem and personal aspirations. Frequent hospital visits, reliance on caregivers, and dietary restrictions can create a sense of helplessness and dependency. Individuals may grieve their loss of autonomy and previous capabilities.

Medical devices (e. g. insulin pumps, dialysis catheters) and physical changes (e. g. fluid retention, weight loss/gain) can lead to negative body image. Scars and physical marks may cause embarrassment or shame.

Individuals may feel they are a burden to their loved ones. A lack of career progression or limited ability to pursue hobbies can diminish their sense of purpose.

8. Financial Stress

The financial burden of managing T1D and CKD is substantial. Expenses include insulin and other diabetes medications, glucose monitoring devices (e. g. CGM, test strips), dialysis treatments incurring additional costs related to limited productivity, part-time employment or unemployment, fatigue and disturbed daily schedule, special dietary requirements, frequent specialist consultations. Frequent medical appointments and physical fatigue can make full-time employment challenging. Job loss or reduced working hours can worsen financial insecurity. Dialysis treatment may lead to financial losses due to incompatibility with many professional activities. Transplant recipients may need to refrain from jobs associated with certain occupational hazards and exposures. Limited insurance coverage for certain treatments or medications can create financial barriers. Navigating insurance policies adds another layer of stress.

9. Resilience and Positive Psychology

Despite the overwhelming challenges, many individuals with T1D and CKD develop remarkable resilience. Some individuals become advocates for diabetes and kidney disease awareness. Volunteering or mentoring newly diagnosed patients can provide fulfillment. Focusing on small daily achievements or meaningful moments can shift perspective from limitations to strengths. Building a reliable support system of family, friends, and healthcare professionals can significantly reduce psychological distress.

10. Psychological Interventions

Collaboration between endocrinologists, nephrologists, psychologists, social workers, and dietitians is essential. Routine screening for anxiety, depression, and burnout should be standard practice for patients managing both conditions. Providing patients with clear, accessible information about their conditions empowers them to actively participate in their care.

11. The Interplay of Physical and Psychological Health

Managing T1D and CKD simultaneously is a delicate balancing act. Poor glycemic control can accelerate kidney damage, while impaired kidney function complicates blood glucose management. However, the impact of these diseases extends far beyond physical symptoms.

Psychological distress, including anxiety, depression, emotional burnout, and cognitive dysfunction, can directly impact treatment adherence and health outcomes.

Physical fatigue and chronic pain can exacerbate emotional exhaustion and reduce the motivation to manage either condition effectively.

This interconnection between physical and psychological health highlights the importance of addressing both aspects simultaneously. Ignoring mental health can lead to poorer medical outcomes, increased healthcare utilization, and reduced overall quality of life [Cogley 2022].

Emotions such as fear, guilt, frustration, and hopelessness are common companions for individuals managing T1D and CKD. Fear often stems from the unpredictability of hypoglycemic episodes or the looming prospect of dialysis or kidney transplantation. Guilt may arise from perceived failures in self-management, while frustration is fueled by the relentless nature of treatment regimens and dietary restrictions [Carta 2017].

12. Key Emotional Takeaways:

- Emotional well-being directly affects treatment adherence and overall resilience
- Therapeutic interventions, including CBT and ACT, are critical tools

in helping patients reframe negative thought patterns
- Peer support groups offer a sense of community and reduce feelings of isolation

Healthcare providers must create an environment where patients feel safe expressing emotional distress without fear of judgment [Akif 2024].

Managing T1D and CKD requires a team-based approach involving endocrinologists and nephrologists for medical care, psychologists and psychiatrists for mental health support, dietitians for nutritional guidance, social workers for resource allocation and support services.

A coordinated care team ensures that no aspect of the patient's health — physical, emotional, social, or financial — is overlooked. Managing T1D and CKD is not just about medical treatment — it's about addressing the human experience of chronic illness [Sureshkumar 2006, Sørensen 2007]. By fostering resilience, prioritizing mental health, and building strong support networks, we can improve not only health outcomes but also the quality of life for individuals living with these two challenging conditions.

13. Conclusion

The coexistence of T1D and CKD represents one of the most challenging medical and psychological scenarios in chronic illness management. Both conditions independently demand constant attention, lifestyle adjustments, and emotional resilience, but when they intersect, they amplify each other's complexity, creating a unique set of physical, emotional, cognitive, behavioral, and social challenges. This conclusion aims to tie together the multifaceted aspects discussed, emphasizing the need for a holistic, patient-centered approach to care that integrates medical, psychological, and social support.

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